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Collaborative research in the medical humanities: The case for transdisciplinarity

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Abstract

In this article, we shall discuss the role of collaborative and transdisciplinary research, and its potential for the co-production of scientific and field knowledge that may serve the purpose of the medical humanities. Transdisciplinary research adds to the challenge of interdisciplinary dialogue – that of involving societal stakeholders to whom the research is accountable. The outcome of such research, in terms of generating knowledge that be both scientifically sound and useful for practice, depends on the quality of the partnerships that are created and constantly discussed and adjusted. We argue that the dialogue between researchers, patients, and clinicians, as well as between disciplines and methods, which is key in this type of research, is likely to increase healthcare providers' sensitivity to their patients' emotional and social states and needs, as well as their reflexivity about their own experiences and practices. We are, however, aware of some possible risks and drawbacks associated with this type of research. These are acknowledged and discussed. An important issue in researching the lived experience of chronic illness is that of identity work. We shall use this conceptual category to illustrate, with reference to our own work, the role of triangulating concepts and methods from different disciplines, the role of involving relevant stakeholders in meaningful ways, and the role of the researchers' own subjectivity and reflexivity in constant dialogue with those of the co-researchers, while conducting research on phenomena of significance to the field of medical humanities.

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Introduction

For some decades now, the field of medical humanities has seen a proliferation of works drawing on the humanities, social sciences, ethics, and philosophy to enhance medical training and related research. The medical humanities have played a significant part in defending a vision of care that extend beyond the purely curative or therapeutic aim, the underlying ethos being that care should be apprehended through the multiplicity of the inherent and interconnected aspects of health and illness, rather than through biomedical standards only. Thus, the medical humanities look at the subjectivity and sociocultural backgrounds of all those involved in the experience of illness, as well as the cultural, geographical, and historical contexts underlying medical practices and institutions (Bleakley, 2020; Lefève, Thoreau, and Zimmer, 2020).

Today, while embracing this legacy, the prevailing trend in what has emerged as the 'Critical Medical Humanities' (Whitehead and Woods, 2016) focuses on two main propositions: first, one should not take for granted that medicine, both as a science and a field of practice, will always necessarily benefit from the human and social sciences to gain more sensitivity and reflexivity; second, the boundaries that create norms and routines in the specific disciplinary areas that make up the medical humanities themselves need to be overcome, since the complex issues of contemporary medicine, illness, and health are better addressed through interdisciplinary perspectives. The Critical Medical Humanities are defined by an expanded understanding of the medical beyond clinical settings, a multi-layered analysis of health and illness, and deeper engagement with critical theory, queer and disability studies, and activist scholarship. They emphasize the entanglement of the arts, humanities, and social sciences with biomedical culture, and advocate for a 'robust commitment to new forms of interdisciplinary and cross-sector collaboration' (Viney, Callard, and Woods, 2015: 2).

This expanded scope of the medical humanities should not, however, conceal a core ambition of the field: the idea that medical and paramedical professions need to gain a better understanding of what people in need of care for chronic and/or severe conditions experience physically, emotionally, psychologically, socially, as well as spiritually in relation to their experience of illness. In other words, research within the medical humanities aims to enhance healthcare providers' understanding of the multidimensional challenges involved in navigating complex health conditions. This is expected to make them more receptive to their patients' unique and multifaceted needs, as well as more able to communicate with them in ways that support their autonomy and development and enhance their satisfaction with the healthcare system and the care received.

The aim of this article is to look at how to move, *in practice*, from these valuable epistemological ambitions to the concrete implementation of meaningful research in the

humanities and the social sciences that would serve medicine and healthcare, both as a science and practice. Without rejecting the valuable contributions of the arts, literature, and philosophy to addressing such complex issues, we advocate for the value of more practical approaches that engage a diversity of relevant stakeholders in discussions that enrich both our theoretical and practical understanding of complex phenomena. To this end, we will rely on different experiences of research that we have conducted in our respective fields, that is, public health and clinical psychology. We shall first argue that researching people's experience of illness in order to better prepare healthcare professionals (HCPs) to care for their patients does not only call for *interdisciplinary* but also for *transdisciplinary* research, that is, a type of research where concepts and methods from different disciplines are articulated with the views and experiences of field actors, including patients themselves, in order to co-produce meaningful knowledge and achieve change.

We shall therefore discuss the role of collaborative and transdisciplinary research, and its potential for the co-production of scientific and field knowledge. We argue that the dialogue between researchers, patients, and healthcare providers from different disciplines, which is at the core of this type of research, is likely to enhance the capacity of the healthcare providers involved to further engage with their patients as partners. Indeed, this type of research holds the potential to increase the sensitivity of healthcare providers to their patients' emotional and social states and needs, as well as reflexivity about their own experiences and practices, thus leading to more meaningful patient–provider interactions and personalized care.

With reference to our own work, we shall then move to illustrate the role of several key strategies in the co-production of valuable knowledge, particularly in research aimed at understanding individuals' lived experiences of illness. While we argue that collaborative and transdisciplinary research aligned with the goals of the medical humanities is both necessary and valuable for advancing science and improving healthcare practice and policy, we also recognize the potential risks and limitations associated with this approach. They will be discussed in the last part of this article.

From interdisciplinarity to transdisciplinarity

Drawing from Gunther Tress and colleagues in the field of environmental studies, *interdisciplinarity* may be defined as 'involving several unrelated academic disciplines in a way that forces them to cross subject boundaries. The concerned disciplines integrate disciplinary knowledge in order to create new knowledge and theory and achieve a common research goal' (Tress, Tress, and Fry, 2004: 485–6). On the other hand, *transdisciplinary* research projects are 'projects that involve academic researchers from different unrelated disciplines as well as non-academic participants … Transdisciplinarity thus combines interdisciplinarity with a participatory approach' (ibid.: 487). Transdisciplinary research therefore adds to the challenge of interdisciplinary dialogue – that of involving societal stakeholders to whom the research is accountable and is meant to be useful. The outcome of such research depends on the quality of the partnerships created. These partnerships need to be constantly discussed and adjusted. The aim of such research is, as Daniel

Lang *et al*. put it, to create 'solution-oriented transferable knowledge' that be both useful for societal practice and relevant for science (Lang *et al*., 2012: 27). As we shall illustrate hereafter, we experienced in our own research that knowledge useful for enhancing healthcare providers' understanding of and motivation for more caring practices is best appropriated when these providers are truly engaged and allowed to participate in the different stages of a research project, from setting the research agenda to elaborating strategies for data collection and analysis, as well as discussing emerging results and avenues for their valorization. However, this raises the question of whether the created knowledge may be transferred beyond the context of the collaboration that led to its emergence.

The involvement of patients and their informal caregivers in the co-production of healthcare innovations has gained increased recognition over the last decades (Andersson, Tritter, and Wilson, 2007; Cleemput *et al*., 2019), including through the appointment of User or Patient Advisory Boards to complement traditional steering committees (Koskinas, Gilfoyle, and Salsberg, 2022; Sharma *et al*., 2017). In Health Services Research, participative and collaborative research is increasingly acknowledged as a valuable approach to enhancing our understanding of complex matters, with a solution-focused perspective (Graham *et al*., 2022; Zimmermann *et al*., 2023).

If the purpose of the Critical Medical Humanities is understood as addressing complex and entangled issues in relation to social, health, and illness problems (Whitehead and Woods, 2016: 2), calling for innovative interdisciplinary practices and an encounter between reflective medical care practices and social and human science research perspectives, the outcome of such encounters should be the co-production of a type of knowledge that would not only lead to interdisciplinary academic advances but also to improved practices. However, the prevailing trend in the Critical Medical Humanities features very few explicit methodological accounts of the involvement of patients and healthcare providers as a concrete condition for addressing the complexity of the mentioned entanglement of issues, as it shapes care.

Our work builds upon the legacy of the Critical Medical Humanities in two key ways. First, by engaging in innovative forms of interdisciplinarity that not only move beyond the mere complementarity with biomedical knowledge, but also actively contribute to the renewal of both clinical psychology and public health as academic and professional fields. Second, by asserting that patient participation in research serves as a means to amplify patient voices, foster disciplinary transformation, and enhance the documentation of emerging issues foregrounded by the Critical Medical Humanities – such as the imperative to move beyond traditional medical agendas.

Based on our own experience of conducting research that involves healthcare providers as well as patients considered as experts – through their own valuable lived experience, subjectivity, and cultural contexts – research partners, or co-researchers, we shall now move to highlighting four important strategies that we have put into practice: (a) triangulating *concepts* from different disciplines, (b) triangulating *methods* from different disciplines, (c) involving stakeholders in meaningful ways, and (d) engaging in individual and collective reflective practices. In doing so, we are aware that most of the proposed strategies are common practice in social science research. Yet they are less widely used by scholars in our respective disciplines.

Triangulation of concepts

Identity work is a central issue in researching lived experience of chronic and severe conditions in the medical humanities, clinical psychology, and public health alike. We shall therefore use this conceptual category to illustrate how some processes that are well known to enhance the trustworthiness and credibility of qualitative research (Barbour, 2001; Booth *et al*., 2014; Malterud, 2001) may serve the purpose of the medical humanities. Such processes are particularly suited for addressing the objective of advancing science and improving practice that characterizes transdisciplinary research, as well as for overcoming the challenge of serving as more than just a critical or 'supportive friend' (Whitehead and Woods, 2016: 2) and truly embracing entanglement.

Looking at *identity* as an emblematic concept in various disciplines that seek to understand and conceptualize how chronic conditions are experienced, we propose to start by looking at the interactionist perspective in sociology. Michael Bury first introduced the concept of *biographical disruption* to capture a fundamental aspect of the illness experience among individuals facing serious health conditions (Bury, 1982). Building on this, Juliet Corbin and Anselm Strauss emphasized the critical role of *identity work*, highlighting its interdependence with both *illness work* and *everyday work* in the ongoing management of chronic conditions (Corbin and Strauss, 1985).

The concepts of *identity*, *identity processes*, *or identity work* are however difficult to define precisely, as psychological and social processes are typically shaped by the entanglement of multiple personal and environmental determinants. These interact in complex ways. Such concepts therefore remain an important area for investigation, calling for the interpenetration of several disciplines and methodological approaches. In our own work, which focuses on the lived experience of people with chronic or severe conditions, including adolescents and young adults, we have been able to evidence some aspects of identity processes by looking at the phenomenon under study through an interdisciplinary lens.

Aujoulat, for example, drew several conclusions from an in-depth study on patient empowerment conducted with a sample of patients in different settings and with various somatic chronic conditions. She recognized the importance of addressing issues of psychological safety by taking into account identity-related problems. As a public health and health promotion practitioner and researcher, she found it useful to turn to disciplines such as philosophy (Ricoeur, 1990, 1991, as cited in Aujoulat, Luminet, and Deccache, 2007) and health psychology (Fischer and Tarquinio, 2002, as cited in Aujoulat *et al*., 2008) to enhance her understanding of patient empowerment, as the participants in her study reported a sense of becoming 'a same, yet different person', as originally formulated by Bensaïd in 1978 (Bensaïd, 1978: 27). Moreover, as the participants in her research reported experiencing multiple losses that would threaten their sense of sameness, thus challenging their capacity for self-care, she argued that 'one of the primary aims of an empowering relationship might therefore not be to provide immediate choice and opportunities for participation and self-determination, but to provide reassurance and opportunities for self-exploration instead' (Aujoulat, Luminet, and Deccache, 2007: 783).

Triangulation of methods

Because *identity work* often operates at a pre-reflective level, most of the time it is difficult to put it into words and to hear it in the medical encounter. Revealing such implicit dimensions requires an analysis of the subjective and intersubjective processes that shape care relationships – where care is understood not as a standardized protocol but as a relational dynamic that adapts to the specific context and configuration in which it unfolds (Boge-Olsnes, Risør, and Øberg, 2023). Therefore, beyond the dialogue between disciplines as a means of comparing and integrating concepts in the process of theorizing *identity work* during the experience of illness, we shall now discuss the triangulation of methods from different disciplinary approaches, and its contribution to our research purposes. Such processes are particularly helpful in crossing epistemological boundaries and conducting research more creatively. Yet they are ethically and scientifically challenging.

Two different examples will now illustrate the relevance of combining methods from different disciplines. One example is drawn from the aforementioned research on patient empowerment conducted by Aujoulat, where she combined methods from Phenomenology and Grounded Theory. The second example is from Ricadat's research on sexual identity in adolescents with cancer, where the reference to Grounded Theory was relevant to inform and design research in clinical psychology.

In an in-depth study on patient empowerment, Aujoulat collected personal narratives from 40 patients living with various chronic conditions, focusing on how they expressed their experiences and constructed meaning around their illness trajectories. To gain a deeper understanding of what empowerment means to patients – and how it can be effectively supported by caregivers – she drew on phenomenological methods in the initial phase of her research (Aujoulat, Luminet, and Deccache, 2007). This approach enabled her to identify and describe the circumstances that contribute to patients' feelings of powerlessness in the context of chronic illness. Phenomenological research methods aim to explore how individuals experience and make sense of their world (Moustakas, 1994). Rather than focusing on objective symptoms or clinical data, phenomenological inquiry emphasizes subjective, embodied experience – how illness is felt, how it disrupts daily life, and how it reshapes one's sense of self. This perspective helps healthcare professionals and researchers move beyond the diagnosis to understand how illness is lived, endured, and integrated into a person's life story (Finlay, 2011). Moreover, it enhances researchers' awareness of both the participants' and their own embodied responses, as they share an 'intersubjective relational space' (Burns, 2003, as cited in Finlay, 2006: 28). Aujoulat referred to Grounded Theory in a second phase of her research to generate a theory of empowerment, where issues of reconciling and integrating one's challenged identities to strengthen a coherent perceived sense of self are central (Aujoulat *et al.*, 2008). In her theorization, *taking and relinquishing control* over disease and treatment-related issues while *experiencing safety* in one's social and clinical environments were equally important dimensions in the process of reconciling and integrating one's challenged identities as part of a patient's empowerment journey (Aujoulat, Young, and Salmon, 2012). As other studies have shown, reconciling identities is a key issue in developing motivation and capacity for self-care (Adams, Pill, and Jones,

1997; Aujoulat *et al*., 2014; Tilden *et al*., 2005). Aujoulat's results further suggest that a sense of coherence should be considered a better outcome for patient empowerment than a sense of self-efficacy, as the latter usually focuses on narrow symptom and treatment management issues, whereas a sense of coherence, as defined by Antonovsky and Sagy (1986), also encompasses meaning, a concept strongly related to identity work (Luyckx, Goossens, and Soenens, 2006).

As a practitioner and researcher in clinical psychology, Ricadat aimed to explore the difficulties encountered by adolescents and young adults with cancer in their sexual and romantic lives (Ricadat, 2016, 2023). Indeed, former studies have acknowledged that going through the experience of cancer and treatments has long-term detrimental effects on the quality of young patients' sexual lives (Dobinson *et al*., 2016; Tindle, Denver, and Lilley, 2009; Wettergren *et al*., 2017). Yet, due to the progressive nature of psychosexual development, the precise causes or variables to explain young patients' low satisfaction in their intimate lives, even after full recovery, are not fully known (D'Agostino, Penney, and Zebrack, 2011; Katz, 2014; Moules *et al*., 2017). The reasons for this discrepancy are multifaceted and may be physical, psychological, interpersonal, or social. It is also known that these reasons are deeply related to adolescents' sexual self-construction (Potki *et al*., 2017; Rostosky *et al*., 2008), a process that plays a central role in global identity work. Several authors have acknowledged the need to conduct qualitative and participative studies to complement the results from quantitative ones on such a sensitive and intimate topic (Hordern, 2008; Perz, Ussher, and Gilbert, 2013), and to better meet patients' specific needs when caring for them. Ricadat's research had two aims: firstly, to investigate the subjective and intimate experiences of young patients. Secondly, the practical aim of identifying the interactions with healthcare professionals and care practices that play a role in supporting the psychosexual development of adolescents and young adults. The aim of cross-referencing these two sources of data was improving the care and management of intimacy and sexuality in adolescents and young adults with cancer during acute care and treatment. To this purpose, Ricadat referred to Grounded Theory (Glaser and Strauss, 1967) to collect and analyze her data, and added a participative dimension in her methodological design: the results of individual interviews were discussed and validated by a number of stakeholders. Grounded Theory methodology, borrowed from sociology, produces conceptual categories that are firmly rooted in empirical data, thus yielding results that are in line with the experience of the research subjects, in this case, young patients with cancer. Through its inductive and iterative nature, and its process of investigation by constant comparison, this method enables the formulation of generalizable hypotheses while taking into account the subjectivity and inner dynamics of the participants through their individual narratives, values, and representations (Glaser and Strauss, 1967). Grounded Theory thus provides the science of Clinical Psychology with methodological tools that do not detract from it as a clinical practice. The use of Grounded Theory was framed through the dynamic listening method used in clinical psychology, as it accounts for subtle and complex multimodal care interactions. For example, the analysis of patients' interviews highlighted the crucial role of interactions with their healthcare providers, which they described as very comforting in the course of treatment, including in aspects related to their gendered body, as

supporting their sexual self- and broad identity construction process (Ricadat, 2023). While such dimensions are mostly invisible and usually remain intuitive in clinical psychology research, the combination of methods in Ricadat's study design led to a fruitful dialogue between clinical-based knowledge and scientific validation processes, as other authors have already acknowledged (Anderson, 2006).

As recommended in participative research applied to healthcare (Langley, Wolstenholme, and Cooke, 2018; Papageorgiou *et al.*, 2023), Ricadat's results were enriched through formal deliberative workshops, during which, she asked healthcare providers to discuss and validate the researchers' analyses and interpretations, with a focus on how these might be used for clinical practice. In doing so, the research team moved from an initially interdisciplinary process of analysis to a transdisciplinary one, where relevant stakeholders were involved in meaningful ways.

The involvement of multiple stakeholders in medical humanities research

While exploring patients' perspectives on their lived experiences of illness has been central to our respective research projects, we both encountered a subtle shift – from focusing solely on patients' experiences to also examining healthcare providers' experiences of being confronted with their patients' suffering and attempting to respond to it. Involving different stakeholders appeared as particularly appropriate and happened to increase healthcare providers' practical reflexivity throughout the research processes, thus enhancing the likelihood that the research results might translate into a 'situated knowledge' (Haraway, 1988), which would be more readily appropriated and used to improve practice.

In Ricadat's work (2016, 2023; Ricadat *et al.*, 2023), the involvement of healthcare providers in the participative process of the study was conducted in two stages: first, through collective feedback sessions during which the thematic analyses drawn from the interviews were reported to the healthcare providers, and later through the organization of focus group discussions around emerging research questions and hypotheses. These focus groups discussions, which had been suggested by the healthcare professionals themselves, were meant to provide a space for further clinical and professional reflection and conceptual development. The discussions during these encounters revealed the tensions experienced by healthcare providers in navigating through the dynamics of adolescence and cancer. Healthcare providers reported that tensions were most pronounced when treating young patients who, as a result of their medical treatments, faced the temporary loss of gendered physical characteristics. This often triggers profound identity crises. While the physical changes may be transient, the psychological impact – particularly on adolescents and young adults – can be far more enduring. Such disruptions to identity formation can significantly compromise a young person's sense of self, especially during a developmental stage when the consolidation of sexual and gender identity is critically important. The interactions between the researchers and healthcare providers shed light on the type of relationships and the concrete care and cure practices they established with young patients to support the development of their sexual self under such circumstances (Ricadat, 2023). The discussions that took place during these encounters had a lasting impact, extending well beyond the scope of the study. They influenced

the functioning of the team and contributed to the development of new practices, including the initiation of a training request.

As far as Aujoulat's research on patient empowerment is concerned, relevant stakeholders were involved in both stages of her analysis (i.e. Phenomenology and Grounded Theory). Whereas patients were invited to individually comment in the first stage of the analysis (with reference to Phenomenology) to confirm and enrich the researcher's understanding of their individual experience of powerlessness, healthcare providers – including physicians, nurses, and psychologists – were invited in the second stage of the analysis (with reference to Grounded Theory) to comment on the emerging hypotheses that would explain the process of empowerment in theory, and to reflect on their own practice to find ways to better support their patients' empowerment. As a result of this dialogue, the clinicians confirmed the need to support a sense of psychological safety through addressing patients as persons situated in their unique environments, with preferences and aspirations for self-care that are shaped by their own values, histories, and cultures. Whereas the patients in our sample all shared a common understanding of their experience of feeling disempowered or powerless, their levels of acceptance and type of psychosocial adjustment to their conditions were not equal. This led us to decide not to involve them in the theorization of the process of empowerment. Indeed, as Janice Morse (2015) has explained, to seek respondent validation of an emerging theorization may be counterproductive and inhibit the researcher's ability to explain a phenomenon when, as is the case with Grounded Theory, participants are first purposively and then theoretically sampled to represent a diversity of experiences, and later to confirm or disconfirm emerging hypotheses. In our research, for instance, independently of the type of condition and the time since diagnosis, some people felt quite disempowered at the time of the interview, while other people expressed a greater sense of coherence and mastery. Moreover, participants also had different levels of awareness of their emotions and experiences, and demonstrated unequal reflexive capacity as they produced their narratives.

This is probably one of the limits inherent in using illness narratives as the main source of knowledge in the theorization of subjective experience, a limit which has led some scholars to adopt a critical stance toward the ways in which such narratives are employed within medical humanities (Woods, 2011). Our choice not to involve the patients who participated in our study in the theorization process was therefore also motivated by the ethical concern about creating even more distress for those patients who had expressed feeling disempowered at the time of the interview. This raises the question of how and when to seek patient participation when conducting participatory research on a phenomenon of significance within the field of medical humanities. Continuous reflexivity on the part of the research team and their research partners is recommended to support ethical and methodological decisions at all steps of a research involving vulnerable people (Bogaert, 2022; Dubois, Lahaye, and Aujoulat, 2022).

Working with subjectivity: The role of reflexivity

Qualitative researchers acknowledge the value of subjectivity as being epistemologically relevant to their ways of conducting research (Peshkin, 1994). Indeed, qualitative

research aims to explore human experience, which is intrinsically subjective. Moreover, the collection of qualitative data occurs through the encounter and dialogue, shaped by invisible intersubjective processes, between two (or more) human beings, with their respective personal histories and interests. Lastly, the analysis of qualitative data is done through individual and collective processes of interpretation in which one's disciplinary backgrounds and personal histories also play a role. The results of qualitative research are expected to be trustworthy and transferable (Korstjens and Moser, 2017; Lincoln and Guba, 1985), as opposed to objectified and generalizable results in quantitative data, thus acknowledging that subjectivity plays a role. Yet qualitative researchers are well aware that their results might be biased by their subjectivity if it remained unidentified and unexpressed. Continuous individual reflective practices are therefore recommended as a key strategy to minimize the risk of bias while acknowledging the role of subjectivity.

Reflective practices may include individual and collective strategies to enhance one's self-knowledge and awareness of pre-existing assumptions and representations in relation to a research topic or target population. Reflexivity also serves to reflect on emerging ethical and methodological questions, as well as unexpected results, as they arise during the research process. Moreover, reflexivity allows for the acknowledgement not only of the research participants' vulnerability but also the vulnerability of the researchers themselves, as these are often confronted with sensitive issues and painful experiences while conducting their research. These may have an impact on their own emotional experiences, and sometimes even on their own health and well-being, through a mechanism known as vicarious trauma (Branson, 2019). As qualitative research aims to explore sensitive and often painful issues related to aspects of human experiences, researchers may be exposed to suffering and be affected by other people's emotions as these resonate with their own, affecting them not only as researchers but also as human beings. In addition to informing decisions on scientific orientations and methodological adaptations, reflective processes are therefore also meant to support researchers and co-researchers faced with their own vulnerability throughout the research process. Qualitative researchers' vulnerability as they are exposed to other human beings' suffering – as is the case for social and health practitioners – and how it might negatively impact a research process if it is not sufficiently acknowledged, remains an under-investigated issue, although it has recently gained increasing attention (Ansoms, 2025; Clift *et al*., 2023). As acknowledged by Nadia Bashir following interviews with qualitative researchers, vulnerability might arise in relation to the researcher's 'fear of being on unfamiliar territory; anxiety about the unpredictability of participants; and feelings of powerlessness to help' (Bashir, 2020: 667). In a recent study on the impact of parental burnout on parent–child interactions, Anne-Catherine Dubois, an experienced pediatric and public health nurse and mother of four children, felt the need to be supervised by a systemic and clinical psychologist while conducting her research interviews, in order to reflect on her own emotional experience while collecting and analyzing her data, so as to mitigate a potential risk of bias through identification with the participants' experiences, had this not been identified and expressed (Dubois *et al*., 2024). In another project conducted under the supervision of Aujoulat (Aujoulat *et al*., 2025) – which involved a transdisciplinary team of six

researchers (three senior and three junior) with different clinical and disciplinary backgrounds (medicine, nursing, anthropology, ergotherapy, community health and health promotion, health system research) and a patient partner – on the topic of personalized care planning, the issue of vulnerability emerged for some members of the research team, as they experienced a tension between their roles as researchers and their pre-existing identities as clinicians. In order to help them process their discomfort, as well as to maintain their engagement in the project, a collective process of supervision with a psychologist not involved in the research was initiated. Other authors have reported on the use of journaling to support their own reflexivity in relation to their subjectivity throughout a research process (see e.g. Bradbury-Jones, 2007).

The central role of reflexivity in allowing sufficient flexibility to achieve relevant and meaningful outcomes in qualitative and participative research projects is well acknowledged (see e.g. Abma, 2020; Woelders and Abma, 2019). As highlighted in two literature reviews led by Aujoulat (Dubois, Lahaye, and Aujoulat, 2022; Fløtten *et al*., 2021), which aimed to synthesize existing evidence on the involvement of young people facing difficult life circumstances as co-researchers, such involvement requires careful consideration of the specific interests and vulnerabilities of all stakeholders. It also entails addressing potential power imbalances and ethical challenges that may arise at various stages of the research process.

Moreover, both Ricadat's (Ricadat, 2013; Ricadat *et al*., 2019, 2023) and Aujoulat's (Aujoulat *et al*., 2011) experiences in conducting research that closely involved healthcare providers in collective dialogue and reflexivity about their own practices have evidenced that the benefits of such reflexive processes may extend well beyond the research, and influence the way healthcare providers interact with patients. We argue that the participative and reflective processes involved in transdisciplinary research are congruent with the values and attitudes towards care that healthcare providers are expected to display in practice. In participatory projects, healthcare providers are offered the opportunity to experience how knowledge may be co-constructed through dialogue and reflexivity that deeply respect the different stakeholders' subjectivity, interests, and experiential and scientific knowledge. As a result of this, healthcare providers are empowered to adopt such attitudes themselves in regard to their patients, thus moving from displaying traditional paternalistic attitudes to engaging in partnerships and mutual learning with their patients.

Risks and shortcomings of transdisciplinary research

As we have aimed to illustrate with reference to our own work, engaging stakeholders in transdisciplinary research is essential for the co-production of meaningful research outcomes both for science and practice. In addition, triangulating concepts and methods from different disciplines, while involving stakeholders from the field, offers an avenue for addressing the complexity of the issues that concern the medical humanities, which call for a more critical stance and the acknowledgement that there is an entanglement of issues that may not be susceptible of reducing to separate disciplinary realities. In line with Abma, we advocate for conducting empowering research where researchers

are the facilitators of a dialogue between different stakeholders in 'mixed research teams' (Abma, Nierse, and Widdershoven, 2009). Indeed, this way of conducting research – where researchers, patients, and caregivers are partners – is congruent with the way medicine and healthcare are hoped to evolve, that is, toward increased partnership and the acknowledgement of patients' active role in their care. However, while we advocate for the broader inclusion of patients in research addressing the complex challenges of living with chronic or severe illness, we also wish to highlight some potential risks and limitations inherent in such research partnerships. First, as Shimmin *et al*. (2017) have put it, we are aware of the risk of essentializing the identity of patients as a homogeneous group, denying important intersecting dimensions in people's lives that contribute to creating complex social identities and vulnerabilities, which are currently under-represented in research on healthcare aiming to involve patients. Thus, even though patient involvement is meant to enhance the relevance and transferability or theoretical generalizability of research findings, it also runs the risk of excluding the voices of those who 'carry the greatest burden of illness, as prevalent research approaches do not sufficiently take into account the impact of the social gradient in health, nor the "inverse care law", when designing approaches to data collection and analysis' (Shimmin *et al*., 2017: 2). Whereas the existence of a social gradient in health points to the fact that social and economic conditions significantly impact people's risk of becoming ill, and their ability to timely and adequately take action to prevent or treat illness (WHO Commission on social determinants of health, 2008), the notion of inverse care law points to the fact that 'the availability of good medical care tends to vary inversely with the need for it' (Tudor-Hart, 1971: 405). Arguing that the same inequity may be found in research that seeks to promote public involvement, Shimmin *et al*. advocate for approaches to participatory research that foster intersectional analysis and acknowledge the role of trauma in health, both in the public and the researchers, so that 'the involvement of people with lived experience leads to improved outcomes for ALL in health research and addresses issues of health equity and social justice' (Shimmin *et al*., 2017: 7). They further argue that the creation of physical and interpersonal environments needs to be carefully considered through reflective and discursive practices that support the safety of both the public and the researchers concerned.

The second risk in relation to participatory research that we would like to address in this discussion is precisely that of failing to attend to some basic needs of the public or the researchers involved, including the need for psychological safety. In a qualitative research that aimed to elicit the experiences of patients as research partners in health research settings, Leese *et al*. (2018) evidenced not only benefits but also possible risks for the patients involved as co-researchers, such as feeling insecure, inadequate, fearful, guilty, or stressed when interacting with researchers. The role of informal spaces to mitigate this risk is highlighted by other authors (see e.g. Bogaert, 2022). In the same research, the hypothesis emerged that there might be possible risks for the researchers as well, in terms of having their contributions discounted 'to the detriment of research quality' (Leese *et al*., 2018: 8).

In Aujoulat's research on personalized care planning (Aujoulat *et al*., 2025), during common analysis workshops and discussions around emerging results, we found

ourselves facing divergent interpretations regarding what should be considered an original outcome. While there was never any doubt concerning what would be considered meaningful or important for the academic and non-academic researchers in the team, the academic researchers sometimes experienced frustration regarding the level of theoretical depth with which to engage. For example, during a collaborative analysis session, both healthcare providers and patients came to recognize the significance of continuity and coherence in relation to identity – dimensions already familiar to the academic researchers through the concept of 'biographical disruption' (Bury, 1982). However, this shared focus led to a de-prioritization of other emerging theoretical questions that had initially sparked the researchers' interest. This highlights the subtle balance to be sought at all steps of a participatory research in order to produce results that be meaningful to all the stakeholders involved. In the aforementioned project, we found it difficult to balance these two dimensions, and this is reflected in our research outputs, as we have so far prioritized accessible publications, webinars, and podcasts. To explore this issue further, Bogaert highlights that patients often navigate between two somewhat incompatible roles: they are, on the one hand, collaborators within a research team that seeks objectivity and generalizable findings, and on the other, individuals invited to share experiential knowledge rooted in personal and subjective experience; 'This dynamic can give rise to tensions' (Bogaert, 2022: 134).

In line with Bogaert (2022), we propose that the level and type of participation sought at different stages of the research process should be carefully considered, openly discussed, and continuously re-evaluated. Participation is not static, it may evolve depending on participants' availability, interests, or shifts in the direction of the project. Indeed, a characteristic inherent to participatory research is that of methodological adaptability to accommodate changing circumstances or unforeseen emerging questions and hypotheses. The need to carefully document not only *if* but *how* various stakeholders, more particularly patients, are engaged in research has recently emerged as an important issue in healthcare and health systems research. In addition to reflexive practices, some authors have recommended the use of checklists to enhance both the conduct of participatory research and the reporting of patient and public involvement in such research (Staniszewska *et al*., 2017).

Conclusion and further perspectives

In this article, we set out to explore how certain aspects of our research experiences might contribute to the Critical Medical Humanities' valuable aim of addressing the challenge of entanglement in a practical way while engaging with the complex and intertwined issues that have been central to the medical humanities since their inception.

Drawing on our respective backgrounds in public health and clinical psychology, we reflect on how their shared ambition to produce actionable knowledge for practitioners and policymakers can support meaningful change. In doing so, the limitations inherent to any single disciplinary perspective become apparent, as do the rich contributions made possible through interdisciplinary and transdisciplinary approaches. Individual researchers may feel enriched by such cross-fertilization of concepts and methods from

different disciplines, yet it is also possible that this might create a sense of uncertainty for scholars with strong disciplinary backgrounds.

Moreover, engaging with societal actors, including patients – who are traditionally defined as vulnerable people who should be attended to by services and research pertaining to healthcare, rather than as contributing to research in practice – led us to look differently at what it means to produce knowledge, and to embrace a solution-focused lens. This brings us to another dimension of what we consider the purpose of the medical humanities should be, which is to reflect on how doctors (and by extension, any healthcare provider) might be best prepared for the clinical encounter. Although this is beyond the scope of our article and will therefore not be developed further, we wish to advocate not only for the co-production of knowledge but also for the co-design and co-implementation of teaching curricula for healthcare providers, if the purpose of the medical humanities is to be fully embraced. This, in turn, calls for further research on how, why, and under what circumstances partnering with patients in the training of medical and paramedical students may have a positive impact on how healthcare providers and patients interact in practice later on. In other words, this raises concerns about the capacity of such partnerships to address existing power imbalances inherent in the patient–provider relationship, bearing in mind that some groups with additional vulnerabilities that intersect with the vulnerability of being sick are unfortunately still underrepresented in most research and trainings. The ethical and methodological challenges related to involving patients and health services users in ways that contribute to the empowerment of all, and not only the most literate, so as to avoid further increasing existing health inequities remains yet an under-investigated issue.

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