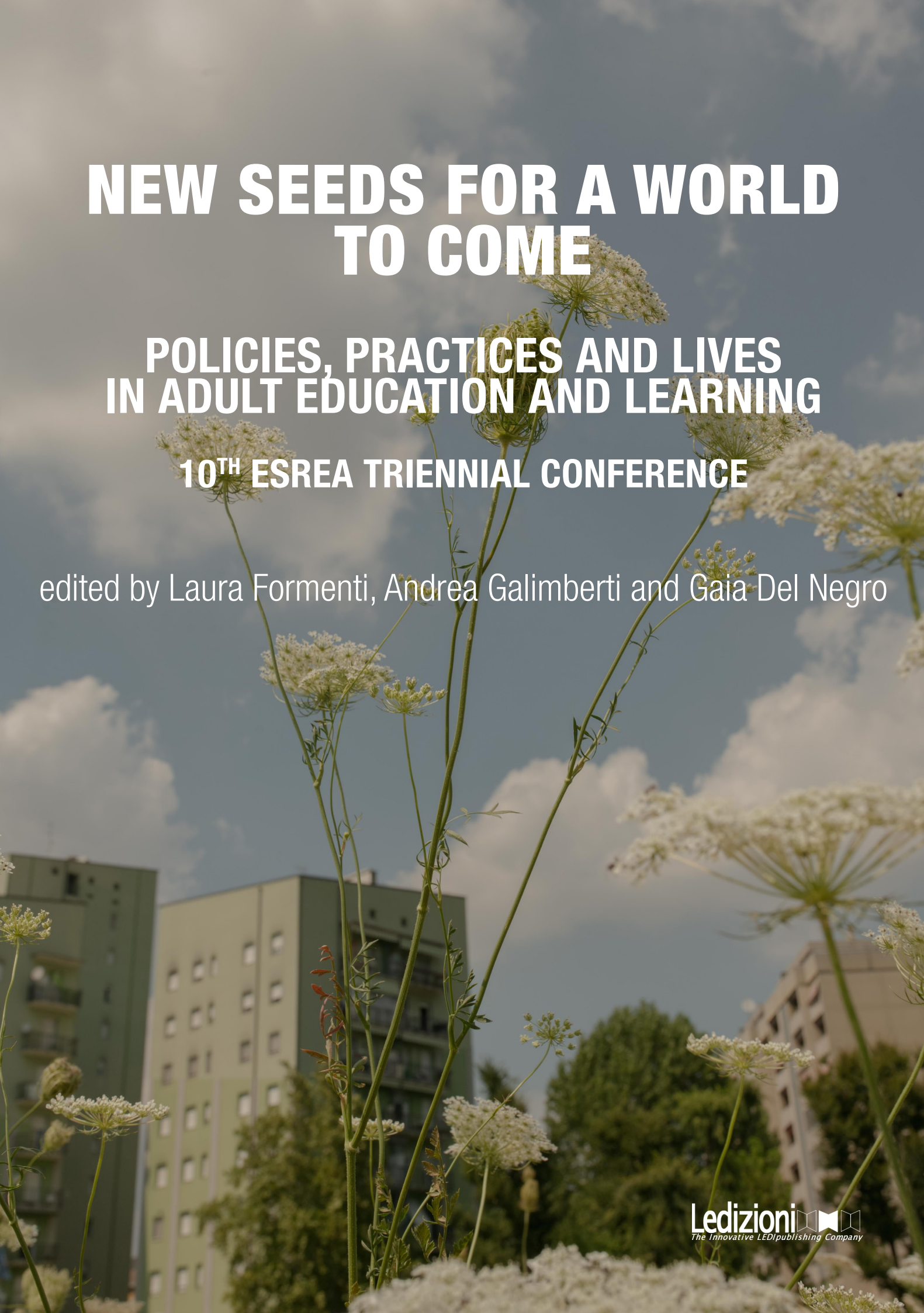

NEW SEEDS FOR A WORLD TO COME

POLICIES, PRACTICES AND LIVES IN ADULT EDUCATION AND LEARNING

10TH ESREA TRIENNIAL CONFERENCE

edited by Laura Formenti, Andrea Galimberti and Gaia Del Negro

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Proceedings of the 10th ESREA Triennial Conference
University of Milano Bicocca,
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Symposia

Chronicity and Pandemic: Research Perspectives and Educational Actions to Support, in Changement, the Adult with Chronicity

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Abstract - The pandemic has introduced new elements of complexity in the existence of subjects, exposing them to unprecedented forms of fragility. These considerations take on greater meaning in the chronic condition in which such complexity must be reconciled with the tasks of the management of the disease. Starting from the results of a qualitative research on the formative dimensions in the self-management of diabetes, the paper highlights the contribution that the socio-material perspective on the chronicity experience can offer in outlining new research possibilities and educational actions that activate transformative resilience processes, to support the subject in living current life scenarios.

KEYWORDS: Chronicity, pandemic, socio-material approach, complexity, education.

1. EXPERIENCING COMPLEXITY BETWEEN LIMITS AND POSSIBILITIES

The dramatic changes, introduced by the pandemic in the past two years, have sparked the debate on the issues regarding health and well-being of individuals and communities, highlighting their multifactorial and procedural character.

Being healthy and feeling well are not static conditions, solely attributable to the absence of disease but they are processes of continuous interaction, among biological, psychological, social and material components, in search of ever-changing balances.

From this perspective, while pursuing the objective of protecting the community health against the pandemic, something crucial seems to have gone missing: the eco-systemic and highly complex character of individual and collective health, which emerges by decentralizing attention from the strictly biological dimension of individuals and expanding it to their actual existential experience (Cucuzza, 2021; Zannini, 2003).

When facing such complexity, in which the medical-health paradigm is kept in check by its exclusive focusing on the biological level of the disease, creative forms of thinking are needed, capable of grasping the relationships between the different dimensions of the subject's life so to build sustainable life paths.

In fact, alongside a necessary thought "on the limit" materialized in the implementation of indispensable containment strategies for the reduction of infections, what is really missing seems to be a thought "on the possible" which, starting from a reflection on the impacts of the constraints imposed on the experience of the subjects, questions about the resources that can be activated to find new balances in coping with the situation.

These considerations take on greater significance if contextualized in the context of chronicity, an ever-increasing condition in the world, in the presence of which we are witnessing an amplification of the negative impacts of the pandemic both with respect to the treatment practices and to the course of the disease and in terms of quality of life of the subjects: the necessary reorganization of health services has often led to the deferral of scheduled services with the risk of a reduction in the quality of care; the rules to avoid contagion have added further obligations and daily attentions to those already necessary for the management of the disease; the greater vulnerability to severe and lethal forms of Covid-19 in patients with previous chronic diseases, resulting from the scientific evidence available to date (http://www.epicentro.iss.it/en), has increased the levels of anxiety and stress that subjects in these conditions must face and has often made social distancing even more drastic, increasing the subjects' difficulties in terms of participation and involvement in the common consortium.

Such condition challenges the pedagogical knowledge to "think what is possible" to understand how to support the individual in change and accompany him while pursuing his own life project.

In order to understand such complexity, it is important to approach the theme by grasping the multidimensionality of the subject's experience and the intertwining of individual, social and material components.

Socio-material approaches (Fenwick et al., 2011), focusing on the entire system of relationships between social and material elements, allow us to take a look that restores complexity to the experience, thus opening up new perspectives of research and educational actions that support the adult subject with chronicity in inhabiting new life scenarios.

Below, starting from the results of a qualitative empirical research on the formative dimensions in the self-management of type-1 diabetes in the adult patient (Cucuzza, 2021), the contribution that the adoption of a socio-material outlook can offer in studying the experience of chronicity will be explored, so to later "open up to the possible" through a reflection on the implications of such approach in the education of adults in this condition, in order to activate paths that can support them in facing the complexity of the present times.

2. EXPLORING CHRONICITY THROUGH A SOCIO-MATERIAL LENS. THE CASE OF TYPE-1 DIABETES

2.1. The scope of the research

Type-1 diabetes is a chronic disease requiring the body of the patient to interact with objects, technologies, and procedures without which it could not keep on surviving. Put it simple, such pathology causes an increase in blood sugar levels due to the lack of insulin production by the pancreas, due to the destruction, by antibodies, of ß cells which produce this hormone. Insulin must be injected every day, for life, through multiple subcutaneous injections with an insulin pen or with an insulin pump providing a continuous infusion of insulin into the subcutaneous tissue. In addition to the insulin supply, the management of type-1 diabetes also includes glycemic monitoring, diet and physical activity and is self-managed by patients (http://www.idf.org).

2.2. The research design

The below presented research has the objective of exploring the formative dimensions in the self-management of type-1 diabetes in the adult patient (Cucuzza, 2021), within a socio-material theoretical-methodological framework, through the use of the Actor-Network Theory (ANT) (Ferrante, 2016; Landri & Viteritti, 2016; Latour, 2005). ANT can be defined as a conceptual grid that allows to grasp the nature of relationships within the field of investigation, permitting to focus on the entire system according to a relational epistemic arrangement combined with the attention to the heterogeneity of the elements. Its use has made possible the analysis of the connections between the human and non-human components collaborating in the implementation of self-management necessary practices.

For the realization of the research, in-depth interviews were conducted with adult diabetic people, to deepen the type of experience and learning that different objectual materialities produce in the self-management of type-1 diabetes.

The analysis of interviews, conducted in according with the ANT assumptions, has foreseen the subdivision of the same into thematic units, identifying as a focus the exploration of the ecology of relationships between human and non-human and the analysis of the effects produced by the non-human on the subject's experiences and learning processes.

2.3. The results

Under the socio-material lens, diabetes self-management emerges as an intricate network of interacting social and materials elements. From the analysis of the emerging relationships, such practice turns out to be a useful medical tool for the treatment of the disease on the one hand, and on the other a latent training device tending to build a certain type of methodical subjectivity, functional to the regular fulfilling of the practice. However, the inherent instability of existence with its infinite variables, allows only temporary alignments of elements, in the “here and now” of the situation and places the subject in front of the need, in order to be methodical and self-manage at best, to become flexible and always devising new solutions to implement the needed self-management practices.

The fulfillment of the practice therefore involves a constant process of learning from experience and the development of flexibility, organizational and problem-solving skills, which the subject is not often aware of, and which are not recognized by the care network.

The adoption of a socio-material gaze, through the analysis of the contribution of the social and material components participating in the experience, has made it possible to identify these learnings as the result of situated and heterogeneous networks of actors, opening up to a research work and educational action favoring its acknowledgment and support.

The results of the research are also reflected in the international literature relating to the patient's experience with chronic disease and the learning processes he puts in place to manage it.

In particular, starting from the 1980s, we have been witnessing the development of a research trend that explores the strategic adaptation processes that the patient implements in order to live a valuable life despite the disease (Thorne et al., 2002). This research trend leads to a translation from the traditional focus on suffering, to the discovery of some aspects of the experience of chronicity that are transformative and positive and characterized by the development, by the patient, of skills concerning making decisions and self-care (Thorne & Paterson, 1998).

Furthermore, studies on experiential learning in diabetes, show that this is a continuous process, essential for the learning of coping with the disease (Johansson et al., 2016; Kneck et al., 2014; Kneck et al., 2012; Lin et al., 2008; Low et al., 2016; Paterson et al., 1998; Skrine Jeffers et al., 2019) and often eclipses the more structured inputs provided by the healthcare system (Skrine Jeffers et al., 2019; Wilkinson et al., 2014) becoming the main strategy for dealing with one's condition in daily life.

The above informal training processes, albeit in the specificity of each disease history, can be considered recurrent in the experience of managing chronicity as it is characterized by self-management practices foreseeing strict daily care routines, and they constitute important resources deployed by the subject, that can be brought to light, supported and enhanced by the educational intervention.

3. OPEN TO THE POSSIBLE

The flexibility, problem solving and learning from experience skills that the subject in chronic conditions usually implements for the managing of the disease, have suffered a profound stress with the pandemic.

The introduction of new and unpredictable social and material elements into the existence of subjects has meant, for people with chronic conditions, continuous efforts and responsibilities in an attempt to reconfigure disease management practices based on circumstances, thinking new strategies and accessible practices, to avoid contagion or, in case of disease manifestation, to reconcile therapies and fulfillments with those usually performed, to overcome it in the best possible way.

This precious work, developed at an informal level and very often latent by subjects, risks being lost and not recognized or adequately valued by the subject himself, and, on a broader level, by the entire community.

So, while working with the subject, it becomes important to establish that space of significance that is educational care, with the aim of escorting him towards the existential authenticity, in the continuous search for a balance between its limits and possibilities, whose connotations change constantly (Palmieri, 2012), encouraging processes of transformative resilience understood as the ability to open up to the possibilities of realizing one's life project, valuing internal or external protective factors as elements capable of sustaining and implementing a positive growth (Garista & Zannini, 2003).

To this end, it is therefore important to recognize the internal and external protective factors that can support the subject in the change process. From a methodological point of view, the use of a socio-material perspective allows to analyze the experiential networks that enable the subject to deal with the condition of chronicity, identifying which specific socio-material assemblies can favor and support the learning processes. From this analysis, it is possible to pedagogically reconfigure the experience of managing chronicity, through the opening of fields of educational experience that allow the subject to become aware and process the learning developed during practice, thus supporting him in learning to learn.

The structuring of adult education paths for chronically ill adults in this direction allows to thematize some objects of experience that are particularly stressed in the contemporary scenario, considering the set of individual, social and material factors that contribute to determining them and working on resources and potential.

A first object of experience can be defined as the *toolbox*, referring to the wealth of flexibility, problem solving and learning from experience skills that, as discussed above, the person with chronicity acquires to self-manage his condition and of which he is often unaware. Such object can be thematized through experiences that allow the patient to become aware of the possession of these skills and to learn how to utilize them in the different areas of daily life. The fields of experience that can be activated, in this sense, are many: from activities that transversally solicit organizational and problem-solving skills such as, for example, role-playing games, to structured contexts for the comparison of experiences between peers, or moments of confrontation between patients and medical-health personnel in a vision of the patient as a "carrier of knowledge" acquired by directly experiencing the disease.

A second object is the *unexpected*, in reference to the constantly changing situation and the sudden requests for change that the pandemic has introduced into the lives of individuals. This object of experience can be thematized through the establishment of experiences that present elements of discontinuity and rupture, thus challenging the subject to face them, in a protected situation, thus helping him to become aware, consolidate and strengthen those informal learnings and resources, already developed in coping with the illness and that he can implement in order to cope with the situation.

Finally, a third object of experience is *freedom*, particularly put to the test by the limits and restrictions caused by the pandemic and by the formative and performative pressures implied by the self-management of the disease. This object can be thematized through the preparation of experiences in which the subject can actually feel individual freedom, starting from his own effectiveness, and allowing him to become aware of limits, constraints and characteristics of the context and then, starting from these, identify spaces for action so to pursue one's life project.

In this way the role of a pedagogy of resilience is outlined (Zannini, 2003) which does not reduce the subject to the disease itself and to the limits connected to it but, while recognizing its presence, restores importance to the fullness of the individual's experience and opens to the possible, activating transformative practices in this regard.

4. CONCLUSIONS

The contemporary scenario, in constant change, challenges the subject to think of himself as in transformation, to think of transformation (Ferrante, 2014), to live in transformation and, consequently, challenges pedagogy in supporting him with such task.

The adoption of a socio-material approach highlights how the transformation, as well as the transitions from a state of illness and uneasiness to a state of well-being and vice versa, are the results of structural processes resulting from the interaction of human and non-human actors, which entail a continuous, complex and uncertain learning process, characterized by an active connection with all the material and social elements of the context (Barbanti, 2016).

From this point of view, change-generating elements are emerging properties of the network and are, in turn, recognizable through the socio-material analysis of the training processes actually implemented or in action (Barone, 2007).

The analysis of the mentioned elements allows to pedagogically reconfigure the experiences by intervening on materiality in order to design and encourage new forms of action in which it becomes an ally (Viteritti, 2017) in supporting the subject in a chronic condition to inhabit new life scenarios.

The recognition of the reticular and systemic character of the experience and of the learning processes involving the subject, invites a widespread intervention that calls to the various actors engaged, enhancing the resources and potential of the interaction between the subject, the social and material context of belonging, favoring not only the transformation of the individual but also the development and growth of communities, with a view to reciprocity.

This intervention acts in contrast to the prevalent welfare logic in the management of the disease, favoring the empowerment of the person in this condition and participation in the community. It also helps to promote a new culture in the community in the approach to chronicity, deconstructing the representation of finitude and passivity attributed to it in the common sense.

This way, new research perspectives are opened up which, starting from the study of the relationships among the different elements of the formative structure agent, interpret complexity, outlining educational actions capable of recognizing, thematizing and respecting it, thus helping the chronically ill subject to live the present time, improving his quality of life, and promoting community development and the economic and social sustainability of the practice.

References

Barbanti, C. (2016). La scuola: una miriade di assemblaggi sociomateriali. Nuovi quesiti, processi e oggetti nella ricerca in ambito educativo attraverso l'approccio dell'Actor-Network Theory. *Scuola Democratica. Learning for Democracy*, *7*(1), 183-198. https://doi.org/10.12828/83018

Barone, P. (2007). *La materialità educativa. L'orizzonte materialista dell'epistemologia pedagogica e la clinica della formazione*. Unicopli.

Cucuzza, G. (2021). *Materialità e cura. Gli effetti formativi degli oggetti nell'autogestione del diabete di tipo 1 nel paziente adulto*. FrancoAngeli.

Fenwick, T., Edwards, R., & Sawchuk, P. (2011). *Emerging Approaches to Educational Research: Tracing the Sociomaterial*. Routledge.

Ferrante, A. (2014). *Pedagogia e orizzonte post-umanista*. LED.

Ferrante, A. (2016). *Materialità e azione educativa*. FrancoAngeli.

Garista, P., & Zannini, L. (2003). Tempo per sé e salute: la prospettiva della resilienza. *Adultità*, *18*(2003), 128-137.

Johansson, K., Österberg, S. A., Leksell, J., & Berglund, M. (2016). Patients' experiences of support for learning to live with diabetes to promote health and well-being: A lifeworld phenomenological study. *International Journal of Qualitative Studies on Health and Well-Being*, *11*, 31330. https://doi.org/10.3402/qhw.v11.31330

Kneck, Å., Fagerberg, I., Eriksson, L. E., & Lundman, B. (2014). Living with diabetes-development of learning patterns over a 3-year period. *International Journal of Qualitative Studies on Health and Well-Being*, *9*(1), 24375. https://doi.org/10.3402/qhw.v9.24375

Kneck, Å., Klang, B., & Fagerberg, I. (2012). Learning to live with diabetes - integrating an illness or objectifying a disease. *Journal of Advanced Nursing*, *68*(11), 2486-2495. https://doi.org/10.1111/j.1365-2648.2012.05947.x

Landri, P., & Viteritti, A. (2016). Introduzione. Le masse mancanti in educazione. *Scuola Democratica. Learning for Democracy*, *7*(1), 7-22. https://doi.org/10.12828/83010

Latour, B. (2005). *Reassembling the Social: An Introduction to Actor-Network Theory*. Oxford University Press.

Lin, C.C., Anderson, R.M., Hagerty, B.M., & Lee, B.O. (2008). Diabetes self-management experience: a focus group study of Taiwanese patients with type 2 diabetes. *Journal of Clinical Nursing*, *17*(5), 34-42. https://doi.org/10.1111/j.1365-2702.2007.01962.x

Low, L.L., Tong, S.F., & Low, W.Y. (2016). Selection of Treatment Strategies among Patients with Type 2 Diabetes Mellitus in Malaysia: A Grounded Theory Approach. *PLoS ONE*, *11*(1), e0147127. https://doi.org/10.1371/journal.pone.0147127

Palmieri, C. (2012). *Crisi sociale e disagio educativo. Spunti di ricerca pedagogica*. FrancoAngeli.

Paterson, B., Thorne, S., & Dewis, M. (1998). Adapting to and Managing Diabetes. *Image: journal of nursing scholarship*, *30*(1), 57-62. https://doi.org/10.1111/j.1547-5069.1998.tb01237.x

Skrine Jeffers, K., Cadogan, M., Heilemann, M. V., & Phillips, L. R. (2019). Assessing Informal and Formal Diabetes Knowledge in African American Older Adults with Uncontrolled Diabetes. *Journal of gerontological nursing*, *45*(2), 35-41. https://doi.org/10.3928/00989134-20190111-06

Thorne, S., & Paterson, B. (1998). Shifting images of chronic illness. *Image: journal of nursing scholarship*, *30*(2), 173-178. https://doi.org/10.1111/j.1547-5069.1998.tb01275.x

Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic Illness Experience: Insights from a Metastudy. *Background to the method*, *12*(4), 437-452. https://doi.org/10.1177/104973202129120007

Viteritti, A. (2017). La forza delle relazioni tra umani e materialità nei processi educativi. In A. Ferrante & J. Orsenigo, (Eds.), *Dialoghi sul postumano. Pedagogia, filosofia e scienza* (pp. 147-163). Mimesis.

Wilkinson, A., Whitehead, L., & Ritchie, L. (2014). Factors influencing the ability to self-manage diabetes for adults living with type 1 or 2 diabetes. *International Journal of Nursing Studies*, *51*(1), 111-122. https://doi.org/10.1016/j.ijnurstu.2013.01.006

Zannini, L. (2003). *Salute, malattia e cura. Teorie e percorsi di clinica della formazione per gli operatori sanitari*. FrancoAngeli.