

Care as collective work: Transforming public response to family caregiving through Participatory Action Research

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Abstract: This paper examines how public institutions, supported by university researchers in a facilitative role, can develop innovative responses to family caregivers' needs through participatory action research. The experience led to the creation of the *Caregiver Lab*, not merely as a network connecting caregivers and the diverse organizations involved in their support, but as a reflective governance device and co-design arena. Through iterative cycles of listening, dialogue, and collective inquiry, the Lab enabled shared meaning-making, institutional learning, and the co-construction of concrete actions. The study highlights how collaborative infrastructures can address care-related complexity and strengthen democratic participation in welfare systems.

Keywords: Family caregivers; participatory action research; local welfare; co-design

El cuidado como trabajo colectivo: transformar la respuesta pública a los cuidados familiares mediante la investigación-acción participativa

Resumen: Este artículo examina cómo las instituciones públicas, con el apoyo de investigadores universitarios en un rol facilitador, pueden desarrollar respuestas innovadoras a las necesidades de los cuidadores familiares mediante la investigación-acción participativa. La experiencia dio lugar a la creación del *Caregiver Lab*, no solo como una red que conecta a los cuidadores con las diversas organizaciones implicadas en su apoyo, sino como un dispositivo de gobernanza reflexiva y un espacio de co-diseño. A través de ciclos iterativos de escucha, diálogo e indagación colectiva, el Lab favoreció la construcción compartida de significados, el aprendizaje institucional y la co-construcción de acciones concretas. El estudio pone de relieve cómo las infraestructuras colaborativas pueden afrontar la complejidad asociada al cuidado y fortalecer la participación democrática en los sistemas de bienestar.

Palabras clave: Cuidadores familiares; investigación-acción participativa; bienestar local; co-diseño

1. Introduction

Across the world, family caregivers play a crucial role within welfare systems, providing daily support to individuals who are non-self-sufficient or vulnerable due to illness, disability, or advanced age. Informal care work carried out by family caregivers has been estimated to account for approximately 9% of global GDP (Addati et al., 2018). Despite the social and economic significance of their contribution, these individuals often remain invisible, lacking formal recognition, adequate protection, and clearly defined rights. Their condition reflects an

unresolved tension between the private dimension of caregiving and the public responsibility to support care provision (Bongelli et al., 2024; Gagliardi et al., 2022; Viscogliosi, 2024).

Public institutions often struggle to adopt political and social strategies capable of addressing caregivers' complex needs in a systemic and sustainable way. Traditional policies, frequently limited to financial subsidies, prove inadequate when confronted with the multi-dimensional nature of the care burden. It is therefore urgent to move beyond a merely compensatory perspective and build strategic alliances capable of activating an integrated support network involving public, private, and third-sector actors, as well as local communities.

The project presented in this paper follows this direction by adopting a participatory action research approach that is particularly effective for co-constructing and developing initiatives involving diverse social actors. Through participatory and reflexive processes, this practice enables the direct involvement of caregivers, institutions, local stakeholders, and researchers in the co-construction of shared responses grounded in lived experience and emerging needs. Its goal is not only to produce situated knowledge, but also to foster transformative change within the contexts in which it is implemented (Scaratti, 2009; Shotter, 2010; Wallerstein & Duran, 2010).

This contribution examines how a participatory action research (PAR) process can actively guide and sustain transformative actions aimed at improving the conditions of family caregivers within personal care services. Specifically, it highlights how the PAR process supported the co-development of practices and responses grounded in three interrelated axes, social justice, ethics of care, and democratic participation, thereby contributing to ongoing debates at the intersection of action research and welfare transformation. This case study also offers valuable insights for developing models of collaboration between universities and public organizations oriented toward valuing local resources and strengthening community-based welfare systems.

The paper is guided by the following research question: How can a participatory action research approach contribute to the development of useful and shared responses to the needs of family caregivers within a specific territorial context? Building on the assumption that complex and socially relevant problems call for collaborative, reflexive, and action-oriented forms of inquiry (Kemmis & McTaggart, 1988), the study adopts Participatory Action Research (PAR) as both an interpretative and operational framework to explore innovative ways of responding to caregiving needs.

The first part of the paper introduces the local project Caregiver Bergamo – Beside Those Who Care as a case study and discusses PAR as a particularly suitable approach for addressing the complexity of the issues under investigation, given its capacity to integrate experiential, institutional, and professional forms of knowledge within shared spaces of dialogue and learning. In this perspective, the Caregiver Bergamo Lab, which is presented later in the paper, is considered the key context of the research process; it is conceived as a reflective space in which practices, policies, and forms of knowledge can converge and generate new possibilities for action (Schön, 1983). In outlining the methodological approach adopted, particular attention is paid to the construction of the collaboration between the Health Protection Agency (ATS) and the University, as well as to the authors' positionality. The paper then examines the participatory action research process in greater depth, describing the cycles of reflection, planning, and action, along with the concrete measures undertaken to respond to caregivers' needs. Drawing on key learnings that emerged from the process, the discussion presents a