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Analyzing Caregiving with the Fourth Generation of Activity Theory : The Case of Parent Carers of Children with Cancer

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Around 350 million people are care dependent globally, of whom 5% are children above 15^[1]. Managing caregivers of chronic diseases such as cancer requires consideration of the dynamics and complexity of this reality. Worldwide, approximately 400,000 children are diagnosed with cancer ^[2]. Unfortunately, it is impossible today to announce the eradication of cancer and the end of the burden of care related to this pathology. Thus, research objects such as caring are « runaway objects » (Yamazumi, 2020, p. 3) with multiple stakeholders, spaces, and temporalities. Parents of children with cancer live in different localities, have different social backgrounds, and suffer from temporal unavailability. Indeed, parent carers are particularly busy accompanying their child back to school, dealing with post-treatment medical and paramedical follow-up, managing possible siblings, handling the transformation of the relationship with the other parent, returning to work, and taking care of their health.

Our preliminary research shows the predominance of the use of virtual social networks such as Instagram or Facebook by these parent carers. Virtual social networks play a positive role for people with cancer. In the specific case of pediatric cancers, research logically targets the adolescent and young adult populations as users of social networks. This patient population builds a social network of peers to chat about the disease and post-treatment on an emotional and experiential level (Love et al., 2012). Digital 'SMAC' technologies such as social media (Higgins & Clark, 2013) can help to link multiple stakeholders, spaces, and spatiotemporal constraints. Social Media bring, for example, flexibility and a continuous ballet of incoming and outgoing actors, which provides freedom of action for carers.

We are building this on-coming research with a French charity for children with cancer and their families. The objective is to understand better the set of actors around the caring, the coalitions, and especially the everyday objects on which they work. This issue of carers is associated with unpaid work that needs to be socially valued and social justice for these populations weakened by their child's illness, both locally and broadly. For example, in France, the law has considered carers since 2005 but has only granted them leave since 2017. Therefore, we rely on the fourth generation of activity theory and aim to trace the "utopia" (Engeström & Sannino, 2021) historically on carers. Then we would like to identify proximal zones of development linked to a renewed relationship to time and distance through social media. Finally, we target formative interventions with the societal actors of change (Yamazumi, 2020).

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[2] <https://www.acco.org/childhood-cancer-statistics/#:~:text=Globally%2C%20approximately%20400%2C000%20children%20are,their%20second%20decade%20of%20life.>