

Innovating in gerontological coordination. The autonomy of older adults at the center of care work?

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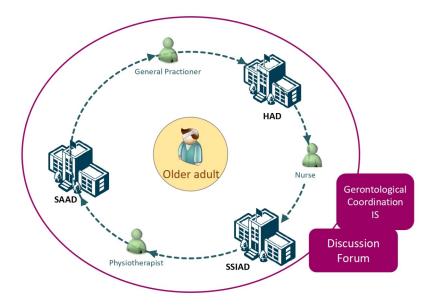
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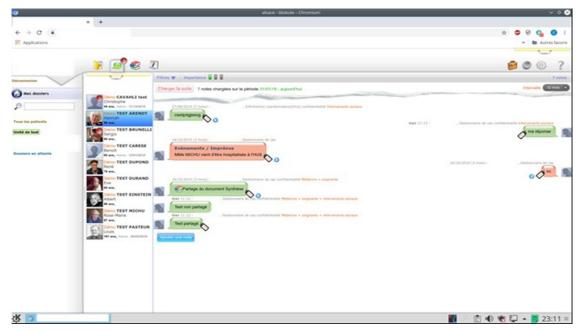
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Innovating in gerontological coordination. The autonomy of older adults at the center of care work?

1) Presentation: This presentation consists in a synthesis of an in-progress paper, which includes some of the results of my PhD thesis. I followed an innovation process applied to the assistance and care of the older adults during four consecutive years in a french department. It concerns the deployment of an information system for gerontological coordination, conceived to promote more efficient exchanges between professionals. To this end, an online discussion forum allows professionals from different sectors (home hospitalization, nursing and assistance services, etc.) to network and keep track of their exchanges.



Each professional involved in a given situation connects to an interface, chooses the level of emergency of the message to be transmitted (green = not very urgent; red = very urgent) and the degree of confidentiality (all professionals / health professionals only / social workers only).



- 2) Problematisation: The French gerontological sector has been mainly described so far in social sciences as organised around the biomedical management of ageing bodies (Bungener, 2004). I thus question if the digital innovation process, has allowed an institutional innovation, leading to transformations in the way of considering older patients (Bonny & Giuliani, 2012). In particular, I analyse the attention paid by professionals to the decision-making power of older people in online exchanges. Knowing that older adults and their relatives do not have access to these exchanges. Greater attention to the autonomy of older adults would then be a sign of institutional innovation. To this end, I propose a definition of autonomy in gerontological intervention at home, in the form of a typology of "forms" of autonomy, concerned by this innovation process.
- 3) Methodology: I deployed a methodological triangulation, crossing participant observations in the home; a quantitative analysis of online exchanges; semi-structured interviews with care professionals, older adults and relatives (N=41) for 9 targeted situations, to account for the impact of the innovation process on interactions at home; semi-structured interviews with the IS project managers. In addition, qualitative analyses of the discussion forums of the patients met (2 or 3 patients / year) were carried out. In this presentation, I will only focus on the qualitative approaches.
- 4) A focus on body-at-risk: Concerning the situations I followed in 2016, the exchanges and representations of the professionals interviewed mainly concerned the organisational aspect of care, such as the announcement of hospital admissions and discharges. In 2018, the exchanges also concern the monitoring of vital signs and symptoms that the carers formalise online for the General Practioner. Coordination via the information system is essentially focused on the biomedical management of "bodies-at-risk" (Lòpez and Domènech, 2009), without taking into account the wishes of the older adults. Only <u>functional autonomy</u>, referring to the execution of daily life activities, is supported, by organising the material aspect of assistance and limiting the impact of pathologies.
- 4) Negotiations on Suzanne's forms of autonomy: I met Suzanne in 2017. She was 91 years old. She has been a widow for about ten years and lives alone. She suffers from cognitive disorders due to Alzheimer's disease, but remains relatively autonomous in terms of functional abilities. She categorically refuses to enter a nursing home. At the time of our meeting, a short-term lethal diagnosis had been made, due to severe cardiovascular issues. The case manager calls the other professionals by telephone, so that they can coordinate on a regular basis via the Information System. The aim is to support her wish to die at home. The General Practioner writes in the discussion forum, in response to the nurse who suggests setting up a preventive registration in a nusing home:

He thus becomes the advocate of her <u>moral autonomy</u>, i.e. the fact of making life choices according to internalised social values, which are the basis of the person's identity (In this case: ageing and dying at

home). At the same time, the need to support the securing of home care is asserted. There are also long-term negotiations of her <u>organisational autonomy</u>, i.e. the power she retains over the arrangements of her home. In particular, the case manager writes a note asking whether Susan has agreed to sleep in the healthcare bed. At one point she agreed, but two days later she refused it. In the end, it was her <u>reflexive autonomy</u> that was the subject of long-term multi-partner negotiations, between the different actors involved. Reflexive autonomy refers to a person's ability to assess the correctness of the rules they set for themselves and to conduct a coherent argument. This ability is severely compromised by Susan's Alzheimer's disease.

A negotiation of her <u>decisional autonomy</u>, referring in my definition essentially to the sovereignty of the will (I want to take a nap / I don't want you in my house), concerning help with the toilet by the home care worker, is reported online: "in most cases she refuses help with the toilet but if you ask her nicely she can accept". By doing this, the professionals involved in the network can recognise the value of the care work carried out by home care workers, which is generally invisible and considered insignificant (Laugier, 2020). I also found this type of formalisation in other discussion forums.

5) Conclusion: At the end of my investigations, I do not observe any notable institutional innovation. Online exchanges remain mainly focused on supporting functional autonomy, through biomedical management of body-at-risk. The support of other forms of autonomy (decisional, moral, organisational, reflexive) via the Information System is not related to the evolution of the innovation process, but to the power relations between actors around each situation. Nevertheless, if this remains modest at this stage, I observe that the Information System has made the invisible work of care visible. In my opinion, from the perspective of reflection on care-led innovations in gerontology, it is important to propose a complex definition of autonomy support, by humans networking with non-humans, according to Fabrice Gzil whose work inspired my typology. This definition must take into account the different aspects of the decision-making power of older people, what supports them and what limits them, and not be limited to the compensation of disabilities.

Thank you for your attention