Taking care of the Golem. Reflection on the role of technologies and information sharing in complex care contexts

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Abstract

In this paper, we observe arising issues related to information sharing, comparing the field studies in pediatric palliative care and in nursing homes. In both studies, we explored issues related to continuity of care by focusing on information continuity. In particular, we explored the contrasting opinions of caregivers on how and what information should be shared between relatives and professionals. We used as a theoretical insight the concept of Golem, which provided insightful reflections on the role of technology in such contexts.

Introduction

It is widely recognized that chronic and degenerative ill patients involve a thick network of caregivers whose, in the light of organizational complexities, struggle to communicate and relate each other (Bodenheimer, 2011; Schoen et al., 2005; Wagner, 1996a; Wagner, 2000).

In recent years, it is emerging a need for care services and care technologies focused on chronic and degenerative ill patients in order to support caregivers in providing care collaboratively, communicating over different timing, places, information, and skills (Mc-Gee Lennon, 2008; Postema, 2012; Koch, 2006). However, as stated by Collins and Pinch (1998; 2008), science, medicine, and technology are Golems, powerful but clumsy and dangerous creatures, which enact the mistakes and the successes that humans introject into them with our situated meanings. For this reason, it is paramount to take care of the Golem of technology when designing technologies for complex organizational environments.

Healthcare is an organizational environment that is characterized by heterogeneous actors who articulate their work according to shared understandings and distributed knowledge (Berg, 1999). Data and information need to flow through all the levels of an organization in order to allow coordination and sense-making by supporting actors to relate to each other and articulate their practices. Indeed, since routing the care work on collaboration, coordination and mutual awareness are at the base of quality care (Carman at al., 2013; Strauss et al., 2014; Strauss, 1985; Star & Strauss, 1999; Corbin & Strauss, 1984).

In this paper, we explore the role of technology in supporting continuity of care and information sharing within two healthcare contexts where family and professional caregivers collaborate on the delivery of care.

Our study took place in two end-of-life contexts that take care of patients affected by incurable diseases, who are in the last months or years of their life (Albers et al. 2014; Hudson et al., 2004; Rome et al., 2011; Siegel et al., 1991). The first study analyzes pediatric palliative care (PPC) services, exploring the role of relationships and information sharing in the articulation of care of incurable children at home. The second

study is about nursing homes (NHs), studying relational and information issues between care professionals and relatives of older adults affected by severe impairments.

Both studies focused on how caregivers collaborate, analyzing the practices related to communication and information sharing. To explore the communication routines of caregivers we relied on the theories that discuss the dialectic of data in shifting from information, to knowledge. Specifically, we studied how technology was perceived by professional caregivers and, as results, we obtained both extremely positive and very negative opinions. These results led us to formulate several hypotheses that, eventually, brought us to reflect about the concept of Golem (Collins & Pinch, 1998; 2008).

This paper is organized as follow. The next section discusses the state of the art, providing an overview about information sharing and healthcare technologies. Section 7.3 presents the case studies and the methods that we adopted. Section 7.4 reports the findings of our work. Whereas, section 7.5 presents the discussions, addressing theoretical reflections from our research outcomes.

State of the art

In this section we report the state of the art that composes the framework within which lies this research work. In particular, we present a literature review on healthcare collaborative technologies, drawing attention to their role in information sharing.

Information sharing is deemed an important factor that enhance the work of caregivers, since it provides sense of control and relief from the burden of care (Proot et al., 2003). Within this framework, information continuity, together with the concept of continuity of care, are recognized to be essential in framing how caregivers should take properly care of patients in critical end-of-life conditions (Proot et al., 2003).

Given the often wide network of caregivers that rotate around a patient, continuity of care concerns the alignment of all the communication, relational and organizational needs of the caregivers of critical patients, thus to increase their work efficiency and, subsequently, the quality of care (Grone & Garcia-Barbero, 2001; Wagner, 1996; Wagner, 2000). Whereas, information continuity concerns a specific dimension of continuity of care, which refers to the sense of control and predictability that derives from a clear and consistent information flow related to the care pathway of a patient (Haggerty et al., 2003).

In the next subsections, we discuss the literature on healthcare technologies (see subsection: 7.2.1.), and we address the topic of information sharing (see subsection: 7.2.2.) by presenting the epistemological dialectic between data, information and knowledge.

Healthcare technologies for information sharing

Over the last years, the literature on healthcare technologies and medical information sharing has been focusing on the role of Electronic Medical Record (EMR) in supporting data and information collection, due to the fact that many healthcare contexts experienced the shift from on-paper medical records to electronic ones (Berg, 1999; Wintheireik at al., 2007; Pine et al., 2014).

Studies (i.e. Pine, 2014) discuss the dual role of EMR, stressing its coordinating and accounting roles. On the one hand, EMRs are described as artefacts that embodied policies, making care contexts compliant to laws. On the other hand, they are understood as information tools that support care work coordination and information sharing. In this sense, information sharing supports both transparency and articulation of care work.

The literature suggests that, complying with policies and governmental institutions, the EMRs would increase the efficiency of healthcare contexts, providing clearer information flows that will bring an increase of integrated care work, safety, coordination and available data (Pine et al., 2014; Greenhalgh et al., 2009; Christensen & Ellingsen, 2014). However, these improvements should come along with the standardization of practices among all actors and care units. This subtends the possibility for EMRs to centralize the access to information, to create a structured shared knowledge among caregivers and thus to allow care professionals to operate through standardized practices (Pine et al., 2014; Christensen & Ellingsen, 2014).

Other authors depict a different scenario, describing this view as a technological utopia (Greenhalgh et al., 2009). Indeed, the sense of care work is strongly related to the intersection between unpredictable care contingencies and the enactment of situated practices (Strauss et al., 2014; Strauss, 1985; Star & Strauss, 1999; Corbin & Strauss, 1984; Osterlund, 2013). In this sense, Pine et al. (2014) observed that structured medical information may create negative organizational outcomes that interfere with the coordination of the care work, and it may also entail inaccurate accounts of work. Similarly, Greenhalgh et al. (2009) stress a series of paradoxes, highlighting how in the care delivery there is a strong need of qualitative human work to re-contextualize the medical knowledge in-situ.

These paradoxes are also evident in a series of studies (Berg, 1999; Pine et al., 2014; Christensen & Ellingsen, 2014; Fitzpatrick, 2004; Amsha & Lewkowicz, 2016). Christensen and Ellingsen (2014) investigated medical practices during the process of standardization of information among hospitals promoted by the Norwegian healthcare system, showing that information practices are situated and context related, arguing that standardization seems a "myth because impossible to accomplish across different hospitals" (p. 11). The same issues are investigated by Osterlund (2013), who noted that the distributed knowledge does not lies on how documents spread the knowledge across boundaries, rather on how actors share their knowledge within their shared practices.

Likewise, Fitzpartick (2004) highlights the constant manipulation of on paper medical working records by caregivers. The author explains that caregivers always manipulate the working records, as well as create personal ones, to match the medical records with their situated practices, stressing that the flexibility and tailorability of paper allow caregivers to shape the records according to the trajectory of their work.

Amsha and Lewkowicz (2016) analyzed the potential of coordinative artefacts in sharing medical information, data and documents in an unstructured way since they embrace the situated care practices of the caregivers. They explored the knot-working, studying the need of caregivers to rearrange their care work and their information and data sharing according to the contingencies of the diseases.

The contributions presented above emphasize a polarization between "standardization" and "contingencies of care contexts". This suggests how the design of care technologies should be handled with care (Mol, 2008), making efforts to understand how caregivers perceive structured data and loosely coupled information, and how they intertwine these clues within their situated care practices.

Data-Information-Knowledge

It is widely accepted that caregivers usually share data they have and collect on records that, regardless being digital or on-paper, support information sharing (Fitzpatrick, 2004; Amsha & Lewkowicz, 2016). However, it is also recognized how the knowledge that derives from this data is always indexical and, hence, comprehensible only through the sense-making deriving from situated practices (Berg, 1999; Pine et al., 2014; Christensen & Ellingsen, 2014Fitzpatrick, 2004; Amsha & Lewkowicz, 2016).

Giddens (1979) shows how knowledge is an integral part of social interactions, which allows people to have a collective understanding of their context that reflects social and organizational needs. In this way, the collective understanding frames the organizational knowledge, determining articulation of work and collaborative dynamics.

Managerial studies provided an interpretation on how data, information and knowledge are rooted within organizations and we believe that this view can enrich our analysis on care technologies to support information sharing. In particular, Ackoff (1989) distinguishes between data, information, knowledge, and wisdom, describing these concepts as connected through a logic chain (Ahsan, 2006). Ackoff (1989) proposes the so-called DIKW hierarchy, defining data as symbols that merely represent objects, which turn into information only when they are enriched with explanations and meanings. Ehn (1993) states that artifacts do not exist in isolation, and we believe that data and information do not exist in isolation either. In fact, is the appropriate collection of information that makes them useful and turns them into knowledge Ackoff (1989). The shift from data, information, and knowledge, it is only possible through understanding, which allows people to synthesizer new knowledge from knowledge previously acquired. Lastly, Ackoff proposes wisdom as the ability to move the knowledge towards the comprehension of future perspectives (Bellinger et al., 2004).
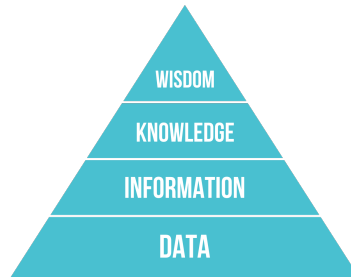

Figure 1: The DIKW hierarchy proposed by Ackoff (1989)

In our opinion, these principles can enrich the understanding of healthcare contexts as well. The chain of sense-making that links data, information and knowledge lies also on the intersections among the situated practices of caregivers. It can also inform the design of collaborative care technologies by highlighting how the data stored by ICTs need to be understood to become information, and how information need to be contextualized to become collective knowledge. Indeed, the shift from data, up to knowledge, passes through the ability of caregivers to articulate their work and to align their meanings according to the illness trajectories Strauss et al., 2014; Strauss, 1985; Star & Strauss, 1999; Corbin & Strauss, 1984). Yet, the knowledge that derives from this is always situated and, hence, comprehensible only through the understanding of the situated practices and the collaborative relationships between caregivers.

These insights guided our investigation on how caregivers perceived information sharing technologies. In particular, the DIKW hierarchy, together with the theory of the Golem (Pinch & Collins, 1998; 2008), helped us to interpret the conflicting outcomes that emerged from the field studies that we conducted in PPC and NHs, supporting us in grasping the nuances of techno-social phenomena in care work.

Methods

This paper includes two studies we carried out within two different end-of-life settings in the northern [State]: a study in pediatric palliative care, a study in a network of nursing homes. The studies were conducted separately because belonging to two different projects.

The PPC study was based on [project name1], a Participatory Design project that aimed to study the care work within home environments to elicit social requirements with the aim to re-design a telemedicine tool.

Whereas, the NHs study was based on [project name2], a project carried out to study relationships between family and professional caregivers in order to develop a collaborative care technology platform.

Both studies were designed to investigate the collaborative care practices of family and professional caregivers,

thus to comprehend how to design new technology platforms to support collaboration among caregivers on the care pathway of patients, while allowing for knowledge and information sharing.

In this paper, we specifically focus on the perspective of care professionals, as their view determined the results of the analysis presented here (see Section 4), and because, in our projects, they had a major role in deciding whether a new technology platform could be adopted within a healthcare environment or not.

We explored the contexts by conducting two in-depth qualitative investigations. Therefore, we relied on semi-structured interviews, focus groups, and observations (see Table 1). The data collection within the PPC was conducted from July 2015 to December 2016. Whereas, the data collection within the NHs was conducted from August 2016 to June 2017. We received the ethical approval from the committee of the University of [town, state] for both studies.

Pediatric Palliative Care		
Method	**Sample/Duration**	**Object/Context**
Interviews	18 interviews with head physicians, medical doctors, nurses, psychologists, social workers and parents of the patients.	We investigated how caregivers perceive their working environment, their mutual relationships, what interfere with their care work, their daily routine, their usage of technology, their collaborative and communication dynamics.
Observations	Several short-term sessions of observations for a total of 50 days of observation.	The short term observations have been guided by sensitizing concepts related to care practices, the daily routine of the caregivers, the communication practices, the factors that either facilitate or hinder the home care work.
Nursing Homes		
Method	**Sample/Duration**	**Object/Context**
Focus Groups	3 focus groups with the care professionals working in the nursing homes.	We investigated the daily routines, the frequency of emergencies, what relatives are worried about and eager to know, what they believe is important to know for the relatives, how they communicate with one another within the staff crew, how they would categorize the relatives.
Interviews	27 family caregivers	We focused on the care practices of the family caregivers, communication practices between them and the staff members, the use of technologies, their opinions about the service provided by the facilities.
Workshops	6 workshops (3 with care professionals and 3 with family members)	We validated the consistency of our findings and we discussed the prototype of a technology to be.

Figure 2: Summary of the methods

Findings

In this section, we present our findings. Here, we highlight the dichotomy of expectations and opinions of the professional caregivers of PPC and

NHs

on the use of a collaborative technology platform to support information sharing. The two case studies, presented separately, are introduced by a short explanation of the research contexts.

Pediatric palliative care

The [project name 1] project aimed to explore the potentials of collaborative technologies in home-care settings, and it was built on a bottom-up and participatory design rationale. As design researchers, we were contacted by a member of a home-care network that provides pediatric palliative services who asked our help to design a collaborative digital platform, in order to support their information sharing among caregivers to render their communication practices more efficient. Therefore, the project rose from the intention of the PPC network to use our expertise to re-design a telemedicine tool, tailoring it upon their needs and context. This revealed their awareness of the issues that were affecting their communication practices, and of the importance of sharing information between family and professional caregivers.

The PPC networks involved in our study provide home-care services to children with incurable diseases. These services are provided at home in order to allow the little patients to be cured in an emotionally safer place, surrounded by their families.

The PPC networks were based on three main groups of actors: (a) the family caregivers who take care of the children at home; (b) the care professionals who are the members of the PPC team that provides the home visits and work side-by-side with the families; (c) the specialists that visit the patients occasionally and prescribe the care plans that are enacted by the PPC team and the families.

The PPC team are composed of different professionals, including paediatricians, nurses and psychologists. Whereas, differently from the care professionals, the families do not usually have any medical knowledge, but they quickly acquire clinical skills by taking care of their children and by being assisted by PPC team. Normally, the family members take care of the little patients autonomously at home, since they are usually visited by care professionals once per week. Hence, family caregivers are usually supported remotely.

The process of home-care of patients in end-of-life conditions requires a close and trustful collaboration between family and professional caregivers, taking care of the frail conditions of the little patients from both human and medical perspectives.

For instance, a doctor said: "We work with the families, we support them and they support us". (Interview with a paediatrician)

Pediatric palliative home-care deals with many different stakeholders, roles, and locations, each one with different degrees of involvement and different knowledge. This entails a complex articulation of work and, subsequently, a low quality of the information flows among caregiver may interfere with the care work. Moreover, the severe conditions of the little patients are often unstable, and they may lead to unpredictable exacerbation or unexpected events in handling medical devices and medications. Care professionals emphasized the delicacy of home-care: "To go at home [of the patients] is always like to enter in the nest, you have to enter gently because you know that if you lose the families' trust you cannot enter anymore in that home". (Interview with a nurse)

Indeed, the home is an informal place that belongs to those who live in it. We observed that, differently form formalized healthcare environments such as hospitals, home-care requires a continuous negotiation of relational and medical boundaries between family and professional caregivers who jointly take care of the patients.

Within this context, the care professionals stated that to take proper care of the patients they need to be aligned on the information they have and share with the family caregivers. They explain that information flow is at the base of the functioning of care pathways, since it allows all caregivers to articulate their work - also remotely - and it allows them to deal with emergencies and unpredictable health conditions of the

patient. Our studies revealed also a widespread use of a commercial mobile instant messaging application among caregivers. Specifically, family and professional caregivers relied on Whatsapp Messenger to share medical data, communicate updates, ask advice, and provide human support to each other.

This multi-sited setting was characterized by dense relationships which entail that the care practices of both families and professionals are inevitably intertwined and distributed. It is evident from our findings that caregivers perceived technologies that supported information flow as fundamental to provide an efficient care, embedding collective sense-making into the care practices.

Nursing homes

The [project name 2] project aimed to design a new IT system to enhance coordination, exchange of medical information and collaboration between the professional and family caregivers of six NHs. The project had a top-down approach, arising from the willingness of the management of the NHs involved and the local authorities to design a technology platform to support communication and relationships between staff members of the NHs and relatives of the patients (residents).

The NHs we investigated are facilities that provide residential care, and work on creating a cosy environment for older adults with several cognitive and physical impairments. The staff members are social-health operators, nurses and one doctor, which follow a strict hierarchy that defines how they articulate their daily tasks and what kind of information they can communicate to the relatives of the residents. NHs generally organize their daily schedules on a series of standard activities with a specific timeline, which is related to the physiological and medical necessities of the residents. To coordinate the care pathway, in recent years, the NHs adopted an EMR (Electronic Medical Record), upon which the staff members collect medical information about the residents. They revealed that they still struggle to use the EMR, which was initially rejected because the work related to data recording increased their workload with no perceived advantages comparing to the old paper records.

In the NHs, the family members of the residents are formally welcome in the facilities and are considered both a resource that can support the staff members and an added patient. For instance, a nurse said: "We welcome the families as patients as well. They are additional patients. We take the whole package". Still, the family members are usually involved in the care pathway of the residents, attending the individual health plan, which is a meeting to plan the treatments for each patient and to formally update the family caregivers on the situation of their loved ones.

"It is right and mandatory to involve the family caregivers" (Focus group - nurse). However, some staff members also stated: "if we want to tackle the situation the right way receiving the family caregivers may interfere" (Focus group - staff member).

For care professionals the involvement of the families is a thorny issue since they are perceived both as useful resources and as actors that can hinder the autonomy of their work. Family caregivers frequently visit the NHs to obtain additional information on their loved ones, but the information that care professionals deliver are often decided according to what they believe is worth to be said to the relatives. Moreover, the tight schedule of the care professionals does not often leave them the time to interact properly with family caregivers.

Conversely, family caregivers also displayed the strong necessity to contribute to the care of their loved ones. They informally articulate the care work with the care professionals, indeed, it is common for them to go to the NHs to feed or to assist their loved ones. Professional caregivers take advantage of this to lower their workload. Nonetheless, they stated that the involvement of the relatives needs to be kept to a certain level to avoid any interference with their care work. According to them, family caregivers lack the competences and the comprehension of the conditions of the residents and of how the care work should be conducted. Therefore, family caregivers are given only the information necessary to understand the condition of their

loved ones, but not the information to comprehend how to intervene on the care pathway. For example, during a workshop, we asked to the care professionals what they thought of a greater involvement of the families in care work, and a nurse provocatively answered that relatives would excessively control the staff by holding them to ransom: "This would be like ISIS!" (referring to terrorism).

It appears that care professionals choose to which extents family caregivers can be involved and informed, as a way to protect their work. This practice emerged as an unwritten rule that does not regard the policies of the NHs, but as a shared practice that care professionals adopted to protect their work and to limit the intrusions and interference of the family members. Professional caregivers admitted to tailor and sometimes avoid to disclose information according to the family caregivers they interact with because they declared to be burdened by the overreactions of the family caregivers.

Somehow care professionals do not want family caregivers to develop a critical knowledge. They wish to keep the boundaries between them and the family caregivers to remain in control of the care path. In this way, care professionals displayed a strong resistance to the development of the new technology platform to enhance collaboration and information sharing between them and the family caregivers. They delivered design suggestions aimed at limiting as much as possible the involvement of the family caregivers. This outcome resulted as antithetical to the initial aim of the project, leading us to a re-shape our intervention within the NHs.

Reflections from our studies

Information sharing in care environments is presented in the state of the art as a mosaic of contributions. Most of the literature refers to studies on EMRs, revealing a polarization between the coordinating and accounting role of information sharing (Winthereik et al., 2007). Yet, efforts in reconciling this view are emerging (Osterlund, 2013). Within care settings, the efforts toward formalization often come into conflict with the situatedness of the contexts themselves. Studies (Christensen & Ellingsen, 2014; Fitzpatrick, 2004; Amsha & Lewkowicz, 2016) emphasize issues related to standardization of medical data, showing how information sharing in healthcare context supports the articulation of situated practices according to the intrinsic contingencies of the care work.

In the light of the literature, we provided an overview of the process through which data become information by acquiring meanings, and by bringing a shared collective knowledge that is at the base of the articulation of care work. There, the quality of the relationships among caregivers is paramount in allowing an alignment of meanings among data, information, and knowledge. Indeed, sharing data and information has the dual role of distributing things that are meaningful, but also the role of aligning meanings, allowing collective knowledge.

In this paper, we presented two studies in end-of-life settings, discussing how technologies to support information sharing are perceived and integrated into the care routines that intersect the efforts of family and professional caregivers.

The two studies yielded opposite results on information sharing dynamics, highlighting the relevance of relational work with family caregivers. In this sense, as paraphrasing Giddens (1979), relationships are needed in care work to contextualize and make sense of data and practices of information sharing itself. These cases show a link between information sharing and relational work since the data to support articulation of work need to become information and knowledge by acquiring sense and aligning collective meaning.

Comparing the outcomes of our studies in PPC and NHs, we noticed that the goals of our studies rose several expectations on the professional caregivers. Moreover, we observed that our idea of delivering a technology platform created enthusiasm among the care professionals working within the PPC, and reluctance in the care professionals working within the NHs.

On the one hand, PPC care professionals displayed a positive attitude towards the possible use of a new technology platform, stressing their eagerness to have an external aid to support their care practices with the family caregivers. Care professionals emphasized that knowledge sharing between them and the family caregivers is a paramount activity upon which the care practices are built and, therefore, they put many positive expectations on the possibility to have a technology platform to support knowledge sharing. Moreover, our findings show that the caregivers used information sharing to make sense of their collective care practices, seeking for meaningfulness, and dealing with the uncertainty of the care conditions of the patients. The project within the PPC networks had a bottom-up approach. The data and the information work was unanimously perceived as enabling of their collaborative practices. In this context, the information symmetry was an essential requirement for the articulation of care work among different places and actors. The data and the information work were framed within a context that considered human relationships among caregivers an integral part of the collaborative care work. This attention to relational work and caregivers' relationships supported the alignment of knowledge that derived from information sharing.

On the other hand, NHs care professionals rose many resistances toward the possible use of a collaborative technology to coordinate the care pathway with family caregivers, since they displayed a reluctance to share too much information with the family caregivers. Differently from the preceding case, the study within the NHs was built on a project with a top-down approach, where the need for a technological solution was pushed by the management of the organizations. There, we found many resistances to information sharing by the staff members. On the one hand, the professional caregivers did not look kindly upon healthcare technologies due to bad experiences with the EMR. On the other hand, staff members were reluctant to share medical data and information with the family caregivers. The staff members were understaffed and unable to have time to nourish the relationships with the relatives, which brought asymmetry of meanings between them and the family caregivers. Hence, the professional caregivers feared the possibility for the data to become information and knowledge that relatives could use to make new requests. The staff members developed an aversion towards joint information sharing with the relatives, in order to protect their autonomy and care work against interference. This study highlighted the resistances of care professionals to the design of a technology to support information sharing, as they aimed to maintain an information asymmetry based on nonknowledge (Bernstein, 2011).

In such contexts, technology was perceived as a golem that if domesticated would have served its scope by enabling alignment of meanings, but without the right shape would have turned into a dangerous creature able to hinder the work of the professionals.

Conclusion

This chapter presented how information sharing among family and professional caregivers is a social, organizational and technological phenomenon that can be perceived as both an enabling and a hindering factor within healthcare settings. It revealed that the design of technologies to support information continuity need to be handled with care. This work suggests that a strategy to take care of the Golem in end-of-life contexts can be to explore collaborative and conflicting social dynamics, analyzing how the dialectic chain that connects data, information and knowledge is contextualized within the relationships of caregivers.

Speaking with the words of Collins and Pinch 27 (p. I), both in PPC and NHs study, technology to support information sharing seems to be either all good or all bad. For some, technology increased the amount of work without advantages, and the information sharing that can emerge from it can be dangerous. For some, technology is an integral part of quality care, supporting collective knowledge, information sharing and coordination of care. Both of these ideas are wrong and dangerous. The personality of technology is neither that of a chivalrous knight nor that of a pitiless juggernaut. Technology is a Golem. A Golem is a

creature from Jewish mythology. It is a humanoid made by man from clay and water. (. . .) It is powerful. (. . .) But it is clumsy and dangerous. (. . .) The Golem is not to be blamed for its mistakes; they are our mistakes.27 (p. I)

Acknowledgements

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