Challenges in future all-round digitalized ASD care services

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Abstract
Considering the estimated prevalence reported by recent studies on Autism Spectrum Disorders (ASDs) and the heavy demand caused by ASD people on families and on educational, social, and medical services, there is a significant and increasing need for effective and efficient care strategies able not only to ensure that ASD persons achieve optimal outcomes and improve their quality of life, but also to support all involved professionals, families, caregivers, and social networks. The potential benefit of ICT-based approach in ASD treatment has been testified by recent literature results regarding, e.g., the exploitation of Virtual Reality (VR) and Augmented Reality (AR) in assistive and cognitive rehabilitation tools. In this position paper we sketch our enlarged vision of ICT-based personalized continuous integrated ASD care services designed under a Socio-Technical (ST) approach and supporting not only ASD treatment but all involved stakeholders, their activities and needs, as well as the interaction among them. The resulting complexity of such overall ST system, the heterogeneity of its components in terms of activities, involved stakeholders, contexts of use (e.g., clinical setting, home setting, schools), and services (e.g., medical guidance, crisis management, real-time monitoring), as well as the necessity for an evolutionary vision of the system and its offered services, demand for a strong unifying conceptual tool around which all system aspects harmonize and cooperate in smart ways for achieving an individual-based continuous care service. In this paper we argue that the adoption of Digital Twin as unifying conceptual tool and its contamination and cooperation with Artificial Intelligence, and VR/AR technologies would be able to boost the achievement of such an ambitious goal, and we discuss possible benefits in typical scenarios related to ASD care (testing, rehabilitation/prosthetic intervention, prediction, crisis management).

Keywords
Digital transformation, Autism Spectrum Disorder, Digital Twin, Virtual/Augmented Reality, AI

1. Introduction

Future health care effectiveness and efficiency – and, ultimately, quality of life – will depend on developing Socio-Technical Systems/Organizations able to address the growing demand of computational, reasoning, and personalization capabilities of digitalized data and procedures and related software. As observed by Clegg, the new technologies "*offer opportunities to work in more interconnected ways, providing scope and catalyst for new working arrangements*" [11]. Convergence and contamination of knowledge and technologies [13] coming from different (and sometimes apparently far from each other) fields may provide for an acceleration of the process and lead to so far unexpected and somehow unimaginable results. Personalized medicine, in particular, may be boosted by the availability of fine-grained information for individual persons allowing the definition of patients' digital models able to favor the tailoring of the treatment and the anticipation of individual patients' responses (see, e.g., [10, 28]).

The 9th International Conference on Socio-Technical Perspectives in IS (STPIS'23) 27.-28.10. Portsmouth, UK
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Digitally supported personalized approaches would represent a significant improvement for example in the treatment of Autism Spectrum Disorders (ASD), where the term *spectrum* underlines the multidimensionality and heterogeneity of the disorder, the manifestations of which vary considerably in relation to the severity of the symptoms, the level of development and chronological age [2, 27, 31], making it difficult to predict which particular intervention approach works best with which ASD individual [54].

1.1. ICT-supported ASD Treatment

In the last two decades, "technology-based treatment" of ASD has gained ever-growing interest: the well-established literature regarding the efficacy of the visual modality for ASD people, with a recognized preference for visual stimuli transmitted through electronic screen media (e.g., [34, 44]) and high engagement with virtual avatars, has made Information and Communication Technology (ICT) a first-class option for the investigation of assistive technologies, cognitive rehabilitation tools, and education tools (see, e.g., [6, 21, 38, 39, 43, 50]). ICT-based tools are generally accepted and enjoyed by ASD people since interaction with computer does not pose sever expectations and judgement issues and allows them to discover conventions in safe and predictable synthetic environments (e.g., based on virtual and/or augmented reality), supports the imagination of people, contexts, and behaviors necessary for role-play, and offers possibility of modifiable multisensory stimulation, replicability, and the definition of individualized interventions (see, e.g., [24 , 26, 36, 50]).

In particular, the use of Virtual Reality (VR) and Augmented Reality (AR) have been investigated in a variety of ASD applications such as neurocognitive assessment, psychotherapy, rehabilitation, prevention and treatment of eating disorder, pain management, social skills training, vocational readiness training, and communication training (as surveyed, e.g., in [39]). Computer-generated representations of real-life environments with realistic appearance seem to have a great potential for teaching social understanding, due to, among others, their capability of replicating social situations that may not be feasible in therapeutic settings with space limitations and resource deficits, promoting role-play within such synthetic scenarios with features and degree of complexity that can be tailored according to the specific ASD individual (see, e.g., [36]). Furthermore, virtual environments can support the interaction of multiple users, favoring group social skills interventions. The survey in [6], for example, reports results achieved in immersive VR training applications conceived for social skill training, life skill training, and safety skill training of ASD individuals through the interaction with customizable task scenarios and social stories in public spaces (like, e.g., a cafeteria or a crowded bus) or focused on school-based and/or home-based (social) activities. A variety of approaches have been used to offer immersive experiences, from CAVE-like projections to Head-Mounted Displays (HMDs), with preliminary results showing transfer of the learned skills in the real life after the treatment.

It must be underlined that the initial fear that the recourse to technology as a treatment tool could exacerbate the isolation of ASD people with difficulties in social relationships has been overtaken by evidence on the success of ICT for improving social interaction when used correctly [43]. In particular, the concern about possible adverse effect of HMDs for immersive VR have been addressed in the literature (e.g., in [7]), and initial findings provide preliminary evidence supporting safety and usability of HMD-based virtual reality for ASD people [55,56], though additional studies are needed in larger samples, larger ranges of VR experiences, and in the context of long-term exposure.

In summary, literature generally agrees on the potential benefits of technology-enhanced approaches, in which a savvy design and the accessibility of the tools would make it also possible to deliver treatment regardless of barriers of distance, time and cost. On the other hand, it has to be observed that studies conducted so far are mainly focused on proof-of-concepts and generally evaluated with too limited clinical groups (also for the objective difficulty in recruiting huge groups of homogeneous participants) as discussed, e.g., in [50,52], with consequent lack of proof for generalization. To have a quantitative measure of the studies' limitations, let us consider, for example, the twenty-four systems surveyed in [6]: four of them do not even specify the number of participants, which, in the remaining twenty, varies from 2 to 26, with an average value of 9.3. Furthermore, scholars have underlined the lack of robust studies with strong methodologies and the lack of consensus on how to do trials (e.g., [21, 38, 52]), along with the need of more research within real educational and clinical settings [7].

1.2. From ICT-based ASD Treatment to all-round ICT-supported ASD Care

We posit that, to move from "emerging" to "established" treatments with proven effectiveness, it is necessary to take one step backward and put the basis for more systematic research by means of a radical change of perspective not only in the studies on technology-enhanced ASD treatment, but also – and beforehand – in the overall management of the ASD person, from testing/diagnosis to treatment/assessment (currently still mostly based on paper-and-pencil approaches) and support on a daily basis in a variety of settings (e.g., home, school, working place, recreational contexts), to be re-designed under a Socio-Technical (ST) approach taking into consideration all stakeholders and their needs. This would lay the foundations for large-scale longitudinal studies in a variety of settings, as well as for an all-round support to the ASD person, taking into considerations all involved actors. The ultimate ideal goal should be an integrated suite of ICT-based tools able to support therapists and operators in diagnosis/assessment/treatment activities, people with ASD in their treatment and daily life, and families, caregivers, and social networks on a daily basis in all aspects of the care of the ASD person. According to an STS perspective, all aspects of the ST system should be interconnected and designed jointly, with no logical precedence of some aspect over the others [11].

The resulting complexity of the overall ST system, the heterogeneity of its components in terms of activities, involved stakeholders, contexts of use (e.g., clinical setting, home setting, schools), and services (e.g., medical guidance, crisis management, real-time monitoring), and the necessity for an evolutionary vision of the system and its offered services demand for a *strong unifying conceptual tool* around which all system aspects harmonize and cooperate in smart ways for achieving an individual-based continuous care service.

We argue that the requirement of a strongly personalized approach, ideally also capable of making predictions on the success of a treatment and/or of anticipating possible critical behaviors, makes *digital twins* a promising approach as such unifying conceptual tool in order to achieve our ambitious goal. Digital Twins (DTs), introduced by Grieves in manufacturing [18, 19, 20], are virtual copies of physical entities, driven by data collected from sensors in real-time to mirror all facets of a product and to co-evolve with the full lifecycle of the physical entities they are associated to. Coped with reasoning capabilities, DTs are used in product design, service management, product life prediction, and real-time monitoring of equipment in industry [30] and are gaining increasing interest also in a variety of fields beyond manufacturing, including healthcare: digital twins of humans would enable the collection and the analysis of physical, physiological, and contextual data to predict potential health problems and support personalized medicine [13, 14, 45]. While the number of scientific papers on DTs in healthcare is significantly increased in the past decade, to the best of our knowledge there is no proposal for their adoption in ASD care and management, probably also because digitalization of ASD related services is really at its infancy.

1.3. Structure of the paper

In this position paper, according to our vision of integrated ICT-based ASD care, we suggest possible applications of DTs for all-round support to ASD persons, healthcare professionals, and social/family networks, surveying in particular which benefits might derive by the contamination and the convergence of DT concepts, AI, and VR/AR technologies. The remaining of this paper is structured as follows. After overviewing in Section 2 the organizational situation of ASD management, with attention to the Italy case, Section 3 overviews the application of DT concepts in healthcare and discusses a possible DT-based digitalized vision of ASD management. Section 4 then discusses associated benefit and concerns and finally, in Section 5, conclusions are drawn.

2. The organizational situation

Autism Spectrum Disorders (ASDs) are characterized by fixated and repetitive patterns of behaviors, restricted interests, and social/communication deficit [2, 54], severely interfering with the processes of building relationships, integrating, and participating into community, and functioning occupationally. In the last decades the estimated prevalence of autism has risen dramatically, as reported by recent studies (e.g., of about 1.5 % in developed countries according to [33], 1 in 68 in the USA [3], about 1 in 100 children in the UK [9], about 0.95% for childhood and adolescence in Central Italy [53]). Even if no definitive reason for such an increase has been determined yet, the growing number of people receiving the diagnosis, considering that the majority require continuous and lifetime assistance in various areas, entails significant costs for the individual with ASD, his family, the health system, and society at large [5, 46]. The "costs" include not only the economic impact on public health but also the burden on the family/caregivers in terms of time, effort, money, stress and, in general, quality of life [31].

Since the ASD person belongs to a system that involves multiple structures and institutions, beside the family and friends' networks, analyzing the socio-institutional context of reference appears to be of fundamental importance to conceive a solution that takes into account the specific needs and requirements of all involved stakeholders.

Related literature. Supporting ASD people and their families is particularly complex, due also to the high necessity of personalization, and requires shared and synergistic work between different professional figures. The lack of adequate collaboration between all the stakeholders involved in taking charge, management and rehabilitation of the person can have negative consequences on the quality of life and on the results of the intervention. The scientific literature [8, 15, 29] underlines the negative outcomes of the fragmentation and lack of integration between the different areas of intervention and treatment (for example medical vs educational), ending up further burden on families. On the other hand, a shared decision-making system would promote a collaborative process for care planning through an ongoing dialogue between the ASC person, caregivers, doctors [4, 23] and local services. In Italy, the law of August 18th, 2015, n.134 ("Provisions on the subject of diagnosis, treatment and qualification of people with autism spectrum disorders and assistance to families") and the institutional agreement between the Government and the Regions ratified by the Conference Unification of May 10th, 2018 ("Updating the guidelines for the promotion and improvement of the quality and appropriateness of care interventions in Autistic Spectrum Disorders") identify national guidelines for the planning of care models and social-health services. The goal is to promote homogeneous protocols for diagnosis and intervention approaches, and coordination between all the involved operational areas based on national and international recommendations. Unfortunately, recent surveys on the Italian territory [5] have underlined the great geographical heterogeneity of child neuropsychiatry services, a poor ability to guarantee the interventions recommended by the guidelines and a fragmentary nature of the operational plans. Often these difficulties are due to poor digitalization of clinical data and the lack of computerized archives for the collection, sharing and recovery of data, which inevitably risks creating gaps in the management of ASD people. The use of IT aids and digital technologies seems to be significantly lower in Southern Italy [5], as confirmed by field studies that we have been conducting.

Field study. A preliminary study was carried out within the framework of the activities of TetaLab (Technology-Enhanced Treatment for Autism Lab), a multidisciplinary laboratory of the University of L'Aquila cooperating with the Regional Reference Center for Autism of the Abruzzo Region and involving psychologists, clinicians, information engineers and computer scientists. The study was part of a more general project aimed at conceiving and validating ICT-based ASD treatments specifically centered on communication, social interaction, and autonomy, and – according to a participatory design approach – also involved ten young persons with ASD in the age range 15-30 and their families as informant. According to our vision, the first phase of the project has been focused on a collaborative analysis of the organizational situation, e.g., of diagnosis and assessment practices to single out possible weakness to ameliorate.

For the initial diagnosis, according to state-of-the-art approaches, individuals that arrive to the centers involved in the project undergo a number of standardizes clinical measures to possibly diagnose ASD, like, e.g., the Autistic Diagnostic Observation Schedule-2 (ADOS-2) [32], an observational assessment of ASDs based on a semi-structured, standardized assessment of communication, social interaction, play, and restricted and repetitive behaviors, to elicit behaviors directly related to a diagnosis of ASD, and the Autism Diagnostic Interview-Revised (ADI-R) [47], a semi-structured, investigator-based interview for parents/caregivers. Once diagnosed as having ASD, individuals undergo a number of cognitive and social cognitive measures, all administered as paper-and-pencil tasks. A primary problem emerged from the analysis: while structure, content, and administration rules of the tasks would clearly allow a straightforward digitalization (most of them are based on simple questionnaires, or short stories integrating images or comic strips and short texts), no computer-based support is available and operators have the burden of integrating results from clinical, cognitive, and social cognitive measures, to record them, analyze them, and plan treatment, thus confirming the results of the previously discussed survey [5].

Other issues emerged from the interviews with therapists, related to long-term relationships with treated kids, with therapists reporting the difficulties, in some cases, to maintain a regular contact with them, e.g., for logistic and/or economic reasons, underlining the necessity of treatment modalities capable to be delivered regardless of barriers of distance, time and cost.

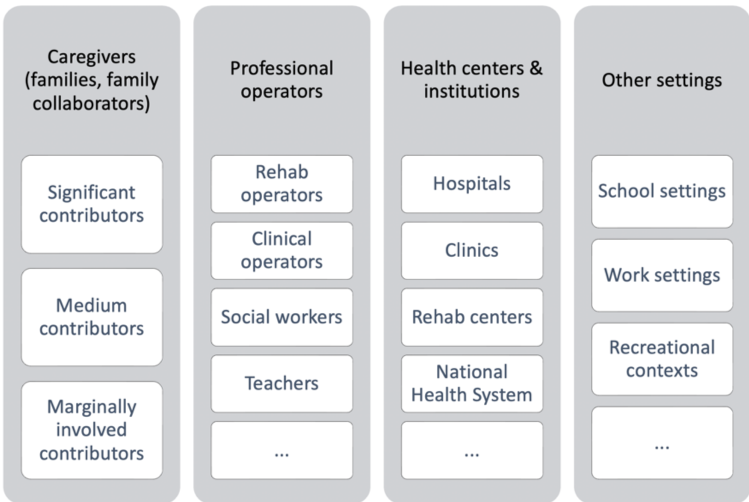

Figure 1: A sketch of the map of stakeholders interacting with an ASD person

Interviews with operators and families [42], combined with observational studies, then led to a general identification of stakeholders, sketched in Figure 1, of their responsibilities, and of the degree and the nature of their interaction with the ASD person. As somehow expected, stakeholders relate to almost all aspects of the life of an ASD person, making the digitalization of all-round support particularly complex. It has also to be observed that we must deal with a complex network of stakeholders with need of communication not only with the ASD person (which anyhow remains the main focus/subject of any communication) but also with each other, with a complex map of information flow and many-to-many communication channels (a detailed analysis of which is out of the scope of this position paper).

Summarizing, stakeholders underlined the necessity of supporting *testing activities, rehabilitation intervention, prosthetic intervention, prediction of treatment efficacy, management of problematic behavior*, and allowed to identify key points related to technology, users, and milieu/environment. In particular, according to such investigation, the technology-based solution should: (1) be customizable and designed according to the person's characteristics, (2) function as a support or an extension of the intervention within which users with autism are already working, (3) provide stimulations to encourage leisure, socializing and activities, (4) take into account deficits and co-morbidities that make it difficult to use the technology adequately, (5) manage problematic behavior. The study made also emerge limitations and concerns, that we will discuss in Section 4 along with a more detailed analysis of the above points in relation to the DT-based vision we propose in Section 3 for testing, rehabilitation/prosthetic intervention, prediction of treatment efficacy, management of problematic behavior.

3. A conceptual unifying tool: the digital twin

In the case of a complex ST system able to provide all-round support to the ASD persons and to the healthcare, social and family networks that revolve around them, it is hence necessary to identify a strong concept able not only to guarantee conceptual and functional coherence to the different aspects of the system but also to guarantee a coherent and sound evolution of a complex system, progressively built and progressively including more and more services and users. In line with both the basic idea of transferring activities from the physical to the digital world and with the objective of placing the ASD person at the center of this complex system, we discuss here the proposal of borrowing the idea of the Digital Twin, recently spread mainly in the Industry 4.0 field but with extremely interesting potential also in health and therapeutic fields.

Notwithstanding difficulties and some confusion [49], studies on and possible application of Digital Twins (DTs) have been ever increasing in the past 20 years, up to the identification of DTs as one of the of the Top 10 Strategic Technology Trends of 2018 [17]. The Digital Twin concept dates back to a 2002 presentation by Michael Grieves for the formation of a Product Lifecycle Management (PLM) center. Although presented as a "conceptual ideal for PLM", the proposal included all the characterizing elements of the DT concept as commonly used today: real space, virtual space, connection for data flow from real space to virtual space, connection for information flow from virtual space to real space, and virtual subspaces, within the context of a dynamic representation throughout the entire life cycle of the system [18, 19, 20]. The proposal somewhat revolutionized the way in which engineering regarded the design of complex systems, moving from a model-centered vision (where multiple instances conform to a unique generic model) to an individual-centered vision (where sensor-based continuous monitoring of a population of physical instances increasingly updates individualized dynamic models), allowing designers and professionals to operate on the digital models for simulations in the production phase, to obtain predictive analysis, and to get support in maintenance activities.

3.1. DT applications in healthcare

Without standards, the definition of a digital twin is not settled yet [49], with different proposals and approaches (see. e.g., [18, 19, 16, 37, 48]). Anyhow, what unites the different proposals and definitions proposed in the literature are: the dynamism of the representation offered by the digital information construct, the continuous exchange of information between digital twins and physical twins, the combination of data and algorithms, the possible use of machine learning and artificial intelligence systems to process data and produce new knowledge, and the idea of complex system. Complex systems are those characterized by large networks of components, many-to-many communication channels, and sophisticated information processing that makes prediction of system states difficult [20, 35]. Interesting enough, as discussed in [20], the common thread to examples of complex systems [41] is "*the human element in interacting with complex systems, which makes these systems socio-technical systems*".

One may notice the analogy between concepts underlying DTs and personalized medicine that, thanks to digital models, promises to tailor healthcare to the anticipated responses of individual patients instead of basing medical interventions on the responses of the average person [10]. This is almost the same conceptual revolution of the shift from model-centered visions to individual-centered visions in engineering and manufacturing, putting the idea of "virtual self" of a patient conceptually on the same par with a DT of a complex and mission-critical artifact [10]. The use of DTs for personalized healthcare is explored for example in [45], which reports on the use and integration of concepts from self-adaptive systems and autonomic computing to a smart and flexible DT-driven healthcare systems focused on chronic disease management (e.g., diabetes). On the same line, [14] proposes an intelligent context-aware healthcare system using the DT framework, validated by an electrocardiogram heart rhythms classifier model built using machine learning to diagnose heart disease and detect heart problems.

The idea of complex system has been brought also to a larger scale, moving from the individual patient to the hospital as a whole, as in [25], which looks at the hospital as an ecosystem that includes real-time services that require high human interaction on resources level (doctor, nurses, etc.) and entities level (patients), and proposes to use the concept of DT of hospital services based on Discrete Event Simulation integrated with health care information systems and Internet of things devices to support designing, planning, improving and controlling the complexity of the ecosystem. Issues related to the complexity (and multitude) of services is investigated also in [30], which aims at achieving interaction and convergence between medical physical and virtual spaces via an extensible framework in the cloud environment for monitoring, diagnosing, and predicting aspects of the health of individuals, especially for the elderly.

The studies discussed so far are just a few examples of the increasing interest around the application of DTs in healthcare. Just to give an idea of how the field is growing, we observe that, while the state-of-the-art surveyed in a 2019 paper could single out 13 studies (with only three of them explicitly about DTs) [40], the query "healthcare digital twin" issued on the Science Direct database in August 2023 yielded the results in Figure 2. Anyhow, to the best of our knowledge, none of the existing studies has been focused on autism treatment.

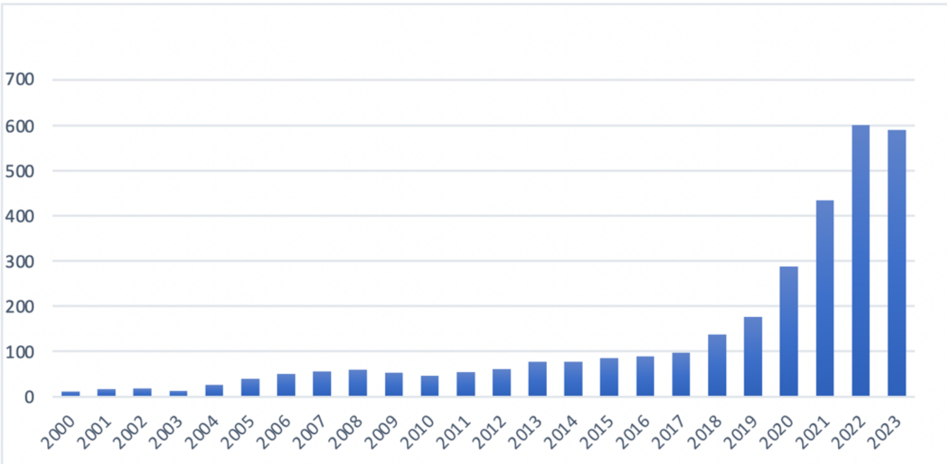

Figure 2: Numbers of papers on digital twins and healthcare in ScienceDirect

3.2. DT application scenarios in ASD care

The lack of studies on the application of DTs in the context of ASD care may be a by-product of the general scarce digitalization in the field. On the other hand, this digital underdevelopment could turn out to be somehow beneficial, since it gives the opportunity to start the digital transformation based on innovative and promising technologies and with more ambitious goals than in the past. In this section, after sketching in Table 1 a possible DT-based view of ASD digitalized management (according to the 5-dimension DT model proposed by [22] for healthcare management), we provide a glimpse of possible ASD digitalized services enhanced by the contamination of DT concepts with AI, VR/AR, IoT.

Table 1
Dimensions of a possible DT model in ASD digitalized management

DT model element	Description in the ASD context
Physical entity	ASD person, operator, setting
Virtual twin	Digital representation of ASD person / operator / setting
Digital twin data	Fusion of fine-grained information including data collected from the ASD person (both historical and real-time), involved operators, physical settings (spatial, environmental), prediction supported by research, ontologies, big data mining and machine learning
Services	Functionalities and services related to the ASD person treatment: reception, testing, diagnosing, monitoring, assessment, personalized treatment, therapeutic intervention, prosthetic intervention, assistance, crisis management, prediction of treatment success, prediction of behavior Functionalities and services related to operational efficiency improvement of healthcare institutions
Data connection	Channels between human and their digital representative (e.g., sensors, app for administrative services, app for treatment)

In theory, DTs can mirror any fact of the associated digital entities. Differently from other healthcare applications, in the case of ASD persons it is crucial to collect not only customary registry, anamnestic, clinical and treatment data, but also all fine-grained information on contexts and individual preferences about daily-life aspects that would allow the DT-based system an automatic high degree of personalization (e.g., which fictional character they prefer, which song they like to listen to, which food they prefer, etc.) for treatment and assistance to ASD persons and their caregiver and for intelligent support to professional operators. Possible DT-enhanced services are the following (the list is not exhaustive):

Testing (DT + multimedia + gamification). Digitalized ICT-enhanced test may be one of the first channels for the collection of DT data, through a communication between the ASD person and their DT via dedicated app. Gamification may also be profitably used to make test sessions more appealing.

Rehabilitation intervention (DT + VR). Social ability may be progressively improved through the interaction with synthetic VR-based environments, possibly experienced by immersive head mounted displays (e.g., Oculus), dynamically and automatically personalized, with varying degrees of realism, scene complexity, sensory enrichment, and immersion, and progressive (automatic and/or operator-controlled) adaptation based on collected data of the DT. Real-life settings attended by the ASD person might be associated to their own DTs and their own VR representations that the ASD person may experience in advance to reduce anxiety in the real-life experience.

Prosthetic intervention (DT + AR). The combination of DT and augmented reality may be the perfect solution for prosthetic tools able to enrich the real world with objects familiar to the ASD person, making the real world less scaring. The augmented personalized world might be experienced at different level of immersion, via translucent visor (e.g., HoloLens), adding a layer of synthetic reality to the natural field of vision, or by simpler app on tablet or smartphone.

Simulation (DT + AI). The combination of DT, AI, machine learning and big data mining might allow operators to simulate interventions on the DT to evaluate their degree of success.

Prediction (DT + AI). The combination of DT, AI, machine learning and big data mining may help to predict the behavior of the ASD person in specific situations, making it possible for caregivers to implement appropriate countermeasures, or even just to know in advance what will happen and prepare themselves for it.

Crisis management (DT + AI + VR+ sensors + IoT). A wide range of possibilities opens up thanx to the combination of DT with AI techniques, VR/AT, sensors and IoT devices, in the handling of crisis and problematic behaviors. Sensors could detect and/or anticipate a state of stress and the DT may intervene by proposing relaxing activities. The physical environment might be enriched with devices (sensors and/or IoT devices) so that DTs could replicate senses of the real twins (e.g., what they see or hear), based on which an automatic or operator-driven intervention is activated. Operators might be associated to their own digital twins and have a virtual representation, as a 3D avatar or hologram, and "appear" to help solving a crisis management by a remote intervention. Generative AI might make the operators' avatars intervene even when they are not remotely available at the time of the crisis.

4. Discussion

The proposed scenarios based on DTs and their contamination with AI and VR/AR technologies may be assessed against the field study previously surveyed in Section 2 as well as against the results of two other studies aimed at (1) identifying priorities and key points for technology-enhanced interventions [42] and (2) evaluating appropriateness and potential of VR/AR head mounted displays as rehabilitation and prosthetic tools [50] The former was conducted by individual semi-structured interviews and involved ASD individuals, caregivers, clinicians, and therapists recruited from across Italy, while the latter was conducted as laboratory experiments and involved ASD individuals recruited within the participants to TetaLab projects. In the following we will refer to these studies as the "field study", the "stakeholders' study" and the "evaluation study", respectively.

4.1. Potential benefits

The core advantage of a DT-based approach is without any doubt its strong support for the personalization non only of the treatment (as advocated by personalized medicine) but of the integrated digital ASD management as a whole.

The benefits related to the digitalization (and possibly gamification) of diagnostic **tests** go beyond the administrative amelioration. An interesting aspect singled out by the field study is in fact related to the relationship between the administering operator and the administered person, with the latter frequently showing discomfort for the presence of the former; for example, in tasks including stories (particularly when of medium size) participants prefer to read the story by themselves and want to feel free to re-read (parts of) it before answering the questions. An interactive multimedia gamified versions of such tests would provide a more comfortable setting for the ASD person.

As to the system components related to the **treatment**, one of the technology-related key points identified by the stakeholders' study was "*make it customizable and designed according to the person's characteristics*". Clinicians underlined that the application should be structured according to the functioning and capabilities of the ASD individuals, while therapists asked for an interface "*calibrated according to who we are dealing with*". It goes without saying that a DT-based approach, capable to maintain a *real-time reflection* of the associated physical entities and *co-evolving with them for their full life cycle*, would be the best possible solution to meet such stakeholders' expectations.

The necessity of personalization and continuous adaptation has been strongly underlined also by the evaluation study: experiment results and post experiment interviews of participants suggested that the design of VR-based **rehabilitation intervention** should be based on the integration of multimedia information at different level of realism (e.g., video, photographs, and cartoon-like images and animations) taking into account subjective familiarity with objects of the virtual environments, which should be able to progress "gradually" from less realistic scenarios towards environments more representative of the real-world, thus facilitating the transfer of skills learned in the virtual environment into everyday life within a process of systematic desensitization.

Clinicians and therapists of the stakeholders' study also observed that the technological solution should be a support or an extension of the intervention within which users with autism are already working, "*something that walks hand in hand with the intervention*", providing integrating functions that can give support on a daily basis. Our vision of an integrated suite of tools shaped according to the concept of DT would be based on *interaction and convergence* of the physical and the virtual world; a system of this kind, guided by socio-technical principles [11], would certainly provide effective answers to stakeholders' demands.

Another crucial key point singled out by the stakeholders' study is related to the support of **problematic behaviors** and **crisis** situations. Clinicians observed that the application should be able to be used in different contexts somewhat "surrounding the person", to detect states of anxiety, and to help the person to return to a state of calm. The evaluation study, on the other hand, suggested the use of HoloLens-like head mounted displays to enrich the real world with objects familiar to the ASD person, thus making it less scaring. The proposed scenarios for crisis management and **prosthetic intervention** provide effective solutions in these directions.

4.2. Possible concerns

On the other hand, it must be observed that the adoption of DT-based systems raises significant technical, methodological, design, and ethical concerns, primarily due to the somewhat immaturity of such technology, particularly in novel application fields.

From a technical/methodological point of view, as discussed also in [49], difficulties may be related to *data* (what types of data must be collected? at which rate? to which extent missing or erroneous data can distort the results?), and *models* (how can one verify the accuracy of the diverse models and of their cooperation within a complex system without consolidated and fully agreed upon standards and guidelines?). From a *design* point of view, we observe that multidisciplinarity of design teams (and the consequent coordination of actors with heterogenous competences) becomes a primary issue for which socio-technical principles and perspectives may play a key guiding role.

As to ethical concerns, DTs can be a double edged weapon with respect to *equality* and *inclusion* issues: [10] observes that if on the one side the approach can function as a social equalizer with significant societal benefits, on the other side it can as well be a driver for inequality, since (1) sophisticated DT-based systems might not be an accessible technology for everyone, and (2) patterns identified across a population of Digital Twins can lead to segmentation and discrimination. Concerns about barriers due to lack of competences did actually emerged also from the stakeholder study: for example, a clinician observed that "*In family contexts where certain competences are not acquired by default, it could be a limitation for the child, a barrier to the use of the devices ... for example, if the child has difficulties, it is possible that parents are not able to help him, which would disadvantage its use in my opinion*.", while a parent pointed out that "*The important thing is that users know what they are using, otherwise they might "label" the technology as overcomplicated and distort the child's use of it accordingly.*".

Another critical point may concern *privacy issues* for all actors involved, which calls not only for advanced cryptography algorithms but also for norms and measures related to ensure data privacy and transparency of data usage and derived benefits, and – more in general – for the resolution of regulatory and political issues [13].

5. Conclusions

In this position paper we overviewed possible applications of Digital Twins in the context of technology-enhanced ASD care, highlighting potential benefits and possible concerns. Given the ASD impact on individual's development and adaptation across the lifespan and its significant distress in daily life even in presence of adequate cognitive functioning, the proposed DT-enhanced approach can have a strong social and economic impact by improving the quality of life for people with autism and their families, possibly allowing to deliver treatment regardless of barriers of distance, time, and cost. We believe that a strong unifying concept as the DT may be beneficial not only from the point of view of the final users and for its natural capability of supporting personalized serviced, but also from a design and development point of view. As a matter of fact, the complexity of a system as the one we envision necessarily requires an evolutionary approach in the design, the implementation and the deployment of component, and a DT-based view would guide a coherent and elegant progressive development of inter-related services.

The next steps in our research in this direction will be carried out in the near future by incoming TetaLab projects, in particular within the framework of the Research and Development programs for "Innovative applications of virtual and augmented reality for people with an autism spectrum condition (ASC)" handled by the Ministry of University and Research and the Agency for Digital Italy (AGID)-Smarter Italy. The forthcoming project includes a prototype realization in the vast Southern Salento area, to be made then exportable throughout the entire national territory. The designed solution integrates HCI, VR/AR and AI technologies, both in the structuring of the intervention and in support in everyday life contexts to guarantee (a) greater involvement, participation and motivation of the ASD person in learning social, communicative and adaptive skills, (b) the personalization of the phases, activities and tools of the rehabilitation intervention, in relation to age and level of severity, (c) the "preventive experimentation" of social situations in a controlled environment, (d) a communication and mediation tool between the ASC person and the "external world" and between the person and the system. The technologies will be implementable on devices that are easy to find and widespread in use, adapting to tools already in use in everyday life.

More generally speaking, the shift to DT-based approaches is meant to relate to a variety of application domains of socio-technical systems in the near future. As observed in [17], "*Over time, digital representations of virtually every aspect of our world will be connected dynamically with their real-world counterpart and with one another and infused with AI-based capabilities to enable advanced simulation, operation and analysis. City planners, digital marketers, healthcare professionals and industrial planners will all benefit from this long-term shift to the integrated digital twin world.*" Such new vision opens up interesting methodological issues in the field of STSs. Let us consider, for example, the hexagon framework proposed by [12] to illustrate the interrelated nature of organizational systems, including the six interrelated elements of people, culture, goals, buildings/infrastructures, process/procedures, and technology. Should DTs implicitly remain within the "technology" element, or should ST methodologies rather take up the challenge of considering new explicit dimensions induced by the digital twins (and more in general by the digital mirror of the real world) in the overall picture the complex organizational systems they aim to model and manage?

Acknowledgements

The investigations discussed in this paper were approved by the Ethical Committee of the NHS Local Health Unit, which approved the experimental protocol prior to the recruitment of participants, according to the principles established by the Declaration of Helsinki. Informed consent was obtained from all the participants before the study.

References

[1] M. Alber, A. Buganza Tepole, W.R. Cannon, et al., Integrating machine learning and multiscale modeling—perspectives, challenges, and opportunities in the biological, biomedical, and behavioral sciences. npj Digit. Med. 2 (2019), https://doi.org/10.1038/s41746-019-0193-y

[2] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-V, American Psychiatric Publishing, Arlington, VA, USA, 2013.

[3] J. Baio, Prevalence of autism spectrum disorder among children aged 8 years autism and developmental disabilities monitoring network, 11 sites, United States, Surveillance Summaries 63 (2014) 1-21.

[4] A. Bejarano-Martín, R. Canal-Bedia, M. Magán-Maganto, C. Fernández-Álvarez, M.V. Cilleros-Martín, M.C. Sánchez-Gómez, ... & M. Posada de la Paz, Early detection, diagnosis and intervention services for young children with autism spectrum disorder in the European Union (ASDEU): Family and professional perspectives, Journal of Autism and Developmental Disorders 50 (2020) 3380-3394.

[5] M. Borgi, V. Ambrosio, D. Cordella, F. Chiarotti, A. Venerosi, Nationwide survey of healthcare services for autism spectrum disorders (ASD) in Italy. Advances in Neurodevelopmental Disorders, 3 (2019) 306-318.

[6] L. Bozgeyikli, A. Raij, S. Katkoori, R.A. Alqasemi, Survey on Virtual Reality for Individuals with Autism Spectrum Disorder: Design Considerations, IEEE Transactions on Learning Technologies 11 (2018) 133-151. doi: 10.1109/TLT.2017.2739747.

[7] R. Bradley, N. Newbutt, Autism and virtual reality head-mounted displays: a state-of-the-art systematic review, Journal of Enabling Technologies 12 (**2018**) 101-113. https://doi.org/10.1108/JET-01-2018-0004

[8] A. Brewer, "We were on our own": Mothers' experiences navigating the fragmented system of professional care for autism, social science & medicine 215 (1982) 61–68.

[9] T. Brugha, S.A. Cooper, S. McManus, S. Purdon, J. Smith, F.J. Scott, F. Tyrer, Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey, The NHS Information Centre, London, 2012.

[10] K. Bruynseels, F. Santoni de Sio, J. van den Hoven, Digital twins in health care: ethical implications of an emerging engineering paradigm. Frontiers in Genetics 9 (2018) doi:10.3389/fgene.2018.00031

[11] C. Clegg, Sociotechnical principles for system design, Applied Ergonomics 31 (2000) 463–477.

[12] M.C. Davis, R. Challenger, D.N.W. Jayewardene, C.W. Clegg, Advancing socio-technical systems thinking: A call for bravery. Applied Ergonomics 45 (2014) 171-180 doi: 10.1016/j.apergo.2013.02.009

[13] A. El Saddik, Digital Twins: The convergence of multimedia technologies, IEEE MultiMedia 25 (2018) 87–92. doi: 10.1109/MMUL.2018.023121167.

[14] H. Elayan, M. Aloqaily, M. Guizani, Digital Twin for Intelligent Context-Aware IoT Healthcare Systems, IEEE Internet of Things Journal 8 (2021) 16749-16757. doi: 10.1109/JIOT.2021.3051158

[15] G. Eyal, B. Hart, E. Oncular, N. Oren, N. Rossi, The Autism Matrix*.* 1st ed. Polity, Cambridge, UK; Malden, MA, 2010.

[16] M. Garetti, P. Rosa, S. Terzi, Life Cycle Simulation for the design of Product-Service Systems, Comput. Ind. 63 (2012) 361–369. doi:10.1016/j.compind.2012.02.007.

[17] Gartner, Inc., Gartner identifies the Top 10 strategic technology trends for 2018, 2017. URL: https://www.gartner.com/newsroom/id/3812063.

[18] M. Grieves, Product lifecycle management: The new paradigm for enterprises. International Journal Product Development, 2 (2005) 71–84.

[19] M. Grieves, Virtually perfect: Driving innovative and lean products through product lifecycle management, Space Coast Press, Cocoa Beach, FL, 2011

[20] M. Grieves, J. Vickers, J. Digital Twin: Mitigating Unpredictable, Undesirable Emergent Behavior in Complex Systems, in: J. Kahlen, S. Flumerfelt, A. Alves, (Eds.) Transdisciplinary Perspectives on Complex Systems, Springer, Cham, 2017. https://doi.org/10.1007/978-3-319-38756-7_4

[21] C. Grossard, G. Palestra, J. Xavier, M. Chetouani, O. Grynszpan, D. Cohen, ICT and autism care: state of the art. Current Opinion in Psychiatry 31 (2018) 474-483. doi: 10.1097/YCO.0000000000000455.

[22] H. Hassani, X. Huang, S. MacFeely, Impactful Digital Twin in the Healthcare Revolution, Big Data Cogn. Comput. 6 (**2022**). https://doi.org/10.3390/ bdcc6030083
[23] S.L. Hyman, S.E. Levy, S.M. Myers, D.Z. Kuo, S. Apkon, L.F. Davidson, ... C. Bridgemohan, Identification, evaluation, and management of children with autism spectrum disorder. Pediatrics 145 (2020).
[24] M.R. Kandalaft, N. Didehbani, D.C. Krawczyk, T.T. Allen, S.B. Chapman, Virtual reality social cognition training for young adults with high-functioning autism, Journal of Autism and Developmental Disorders 43 (2013) 34-44. http://dx.doi.org/10.1007/s10803-012-1544-6.
[25] A. Karakra, F. Fontanili, E. Lamine, J. Lamothe and A. Taweel, Pervasive Computing Integrated Discrete Event Simulation for a Hospital Digital Twin, in: Proceedings of 2018 IEEE/ACS 15th International Conference on Computer Systems and Applications (AICCSA), Aqaba, Jordan, 2018, pp. 1-6. doi: 10.1109/AICCSA.2018.8612796.
[26] U. Lahiri, E. Bekele, E. Dohrmann, Z. Warren, N.A. Sarkar, Physiologically Informed Virtual Reality Based Social Communication System for Individuals with Autism, J Autism Dev. Disord. 45 (2015) 919–931.
[27] M.C. Lai, E. Anagnostou, M. Wiznitzer, C. Allison, S. Baron-Cohen, Evidence-based support for autistic people across the lifespan: Maximising potential, minimising barriers, and optimising the person–environment fit, The Lancet Neurology *19* (2020) 434-451.
[28] H. Lehrach, A.M. Ionescu, The Future of Health Care: deep data, smart sensors, virtual patients and the Internet-of-Humans, 2016.
URL: https://ec.europa.eu/futurium/en/system/files/ged/futurehealth_white_paper.pdf
[29] V. Leiter, The division of labor among systems of therapeutic care for children with disabilities, Journal of Disability Policy Studies 16 (2005) 147-155.
URL: https://ec.europa.eu/futurium/en/system/files/ged/futurehealth_white_paper.pdf
[30] Y. Liu, et al., A Novel Cloud-Based Framework for the Elderly Healthcare Services Using Digital Twin, IEEE Access 7 *(*2019) 49088-49101. doi: 10.1109/ACCESS.2019.2909828.
[31] C. Lord, T. Charman, A. Havdahl, P. Carbone, E. Anagnostou, B. Boyd, ..., J.B. McCauley, The Lancet Commission on the future of care and clinical research in autism, The Lancet 399 (2022) 271-334.
[32] C. Lord, M. Rutter, P.C. Di Lavore, S. Risi, K. Gotham, S.L. Bishop, Autism Diagnostic Observation Schedule (ADOS-2): Manual. 2nd Edn. Western Psychological, Torrance, CA, 2012.
[33] K. Lyall, L. Croen, J. Daniels, et al., The changing epidemiology of autism spectrum disorders, Annu Rev Public Health 38 (2017) 81–102.
[34] B.A. Mineo, W Ziegler, S. Gill, D. Salkin, Engagement with Electronic Screen Media Among Students with Autism Spectrum Disorders, J. Autism Dev. Disord. 39 (2009) 172–187.
[35] M. Mitchell, Complexity: a guided tour. Oxford University Press, Oxford, 2009.
[36] P. Mitchell, S. Parsons, A. Leonard, Using Virtual Environments for Teaching Social Understanding to 6 Adolescents with Autistic Spectrum Disorders, J Autism Dev. Disord 37 (2007) 589–600.
[37] E. Negri, L. Fumagalli, M. Macchi, A Review of the Roles of Digital Twin in CPS-based Production Systems. In Procedia Manufacturing, 11 (2017) 939–948.
[38] S. Parsons, Authenticity in Virtual Reality for assessment and intervention in autism: A conceptual review, Educational Research Review 19 (2016) 138-157.
[39] T.D. Parsons, G. Riva, S. Parsons, F. Mantovani, N. Newbutt, L. Lin, T. Hall, Virtual reality in pediatric psychology, Pediatrics 140 (2017) 86-91. https://doi.org/10.1542/peds.2016-1758I
[40] C. Patrone, G. Galli, R. Revetria, A State of the Art of Digital Twin and Simulation Supported by Data Mining in the Healthcare Sector, in: H. Fujita, A. Selamat (Eds.), Advancing Technology Industrialization Through Intelligent Software Methodologies, Tools and Techniques, volume 318 of Frontiers in Artificial Intelligence and Applications, IOS Press Ebooks, 2019, pp. 605 – 615. doi_ 10.3233/FAIA190084
[41] C. Perrow, Normal accidents: Living with high-risk technologies. Basic Books, New York, NY, 1984.

[42] M.C. Pino, R. Vagnetti, S. Tiberti, M. Valenti, M. Mazza. Involving autism stakeholders in identifying priorities for interventions based on augmented reality. Disability and Rehabilitation: Assistive Technology (2022). doi: 10.1080/17483107.2022.2120103.
[43] B.O. Ploog, A. Scharf, D. Nelson, P.J. Brooks, Use of computer-assisted technologies (CAT) to enhance social, communicative, and language development in children with autism spectrum disorders, J. Autism Dev. Disord. 43 (2013) 301—322.
[44] K. Quill, Instructional considerations for young children with autism: The rationale for visually cued instruction. J. Autism Dev. Disord. 27 (1997) 697–714.
[45] L.F. Rivera, M. Jiménez, P. Angara, N.M. Villegas, G. Tamura, H.A. Müller, Towards continuous monitoring in personalized healthcare through digital twins, in: Proceedings of the 29th Annual International Conference on Computer Science and Software Engineering (CASCON '19). IBM Corp., USA, 2019, pp. 329–335.
[46] N. Rogge, J. Janssen, The economic costs of autism spectrum disorder: A literature review, Journal of Autism and Developmental Disorders 49 (2019) 2873-2900.
[47] M. Rutter, A. Le Couteur, C. Lord, Autism diagnostic interview revised WPS edition manual. Western Psychological Services, Los Angeles, CA, 2003.
[48] F. Tao, J. Cheng, Q. Qi, M. Zhang, H. Zhang, F. Sui, Digital twin-driven product design, manufacturing and service with big data. Int J Adv Manuf Technol 10 (2017) 2233.
[49] F. Tao, Q. Qi, Make more digital twins, Nature, 573 (2019) 490-491. doi: 10.1038/d41586-019-02849-1. PMID: 31554984.
[50] L. Tarantino, M. Attanasio, T. Di Mascio, G. De Gasperis, M. Valenti, M. Mazza, On the evaluation of engagement in immersive applications when users are on the autism spectrum, Sensors 23 (2023). doi: https://doi.org/10.3390/s23042192.
[51] L. Tarantino, G. De Gasperis, T. Di Mascio, M.C. Pino. Immersive applications: what if users are in the autism spectrum?, in: Proceedings of the 17th International Conference on Virtual-Reality Continuum and its Applications in Industry (VRCAI '19), Association for Computing Machinery, New York, NY, USA, 2019. Article 32, 1-7. doi: https://doi.org/10.1145/3359997.3365696
[52] L. Tarantino, M. Mazza, M. Valenti, G. De Gasperis, Towards an Integrated Approach to Diagnosis, Assessment and Treatment in Autism Spectrum Disorders via a Gamified TEL System, in: M. Caporuscio, F. De la Prieta, T. Di Mascio, R. Gennari, J. Gutiérrez Rodríguez, P. Vittorini (Eds.), Methodologies and Intelligent Systems for Technology Enhanced Learning, volume 478 of Advances in Intelligent Systems and Computing, Springer, Cham, 2016, pp.141-149. https://doi.org/10.1007/978-3-319-40165-2_15
[53] M. Valenti, R. Vagnetti, F. Masedu, F. et al., Register-based cumulative prevalence of autism spectrum disorders during childhood and adolescence in Central Italy, Epidemiol Biostatist Public Health 16 (2019). doi: https://doi.org/10.2427/13226.
[54] L. Wilkinson, DSM-5: Rethinking Asperger's Disorder, Autism 2 (2012) e113.
[55] M. Malihi, J. Nguyen, R.E. Cardy, S. Eldon, C. Petta, A. Kushki, A. Short report: Evaluating the safety and usability of head-mounted virtual reality compared to monitor-displayed video for children with autism spectrum disorder, Autism 24(2020) 1924–1929. doi: https://doi.org/10.1177/1362361320934214.
[56] M. Schmidt, N. Newbutt, C. Schmidt, N.A Glaser, Process-Model for Minimizing Adverse Effects when Using Head Mounted Display-Based Virtual Reality for Individuals with Autism, Front. Virtual Real. 2 (2021), doi: https://doi.org/10.3389/frvir.2021.611740.