Research Article

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Wearable robotic exoskeletons: A socio-philosophical perspective on Duchenne muscular dystrophy research

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Abstract: Recently, several research projects in the Netherlands have focused on the development of wearable robotic exoskeletons (WREs) for individuals with Duchenne muscular dystrophy (DMD). Such research on WREs is often treated solely within the disciplines of biomedical and mechanical engineering, overlooking insights from disability studies and philosophy of technology. We argue that mainly two such insights should receive attention: the problematization of the ableism connected to the individual model of disability and the stigmatization by assistive technology. While disability studies have largely rejected the individual model of disability, the engineering sciences seem to still locate disability in an individual's body, not questioning their own problematization of disability. Additionally, philosophy of technology has argued that technologies are not neutral instruments but shape users' actions and perceptions. The design of WREs may convey a message about the understanding of disability, which can be comprehended as a challenge and an opportunity: stigmatization needs to be avoided and positive views on disability can be evoked. This article aims to highlight the benefits of considering these socio-philosophical perspectives by examining the case of WREs for people with DMD and proposing design principles for WREs. These principles may enhance acceptability of WREs, not only by individuals with DMD but also by other users, and help engineers to better place their work in the social context.

Keywords: disability, Duchenne muscular dystrophy, ethics, philosophy, stigma, wearable robotic exoskeletons

1 Introduction

Duchenne muscular dystrophy (DMD) is a neuromuscular progressive disease that affects mainly males, at a rate of approximately 1:5,000 births [1], with 420 reported in the Netherlands in 2013 [2]. The disease leads to progressive loss of muscle strength and deformities (Figure 1a) that result in limited mobility for the affected individuals and subsequently to loss of independence and difficulty to maintain social participation [3]. While the life expectancy of people with DMD has increased [4], due to dependency on caregivers, their self-reported quality of life remains poor [5]. Patient groups have expressed a clear desire for technical solutions, in order to achieve a greater degree of independence by using their own limbs for as long as possible [6,7].

Wearable robotic exoskeletons (WREs) can serve as means to achieve this goal. Such devices can assist in activities of daily living (ADLs) and at the same time enable users to use their own limbs [6], as opposed to external robotic grippers controlled remotely by a joystick and passive splints (Figure 1b) that are often used in DMD [6,7]. Strapped around limbs (see Figure 1c), WREs support and augment the impaired motor function of users. Currently, the main focus in the Netherlands lies on elbow/shoulder [6], trunk/neck [8] and hand/wrist [7] WREs.

However, biomedical engineers often face the rejection of their technology. This is amply demonstrated by the reported rejection rates of prosthetics [9–13] as well as orthotics [14,15]. Reasons for such rejection are discomfort, lack of cosmetic appeal, social restriction, stigma and lack of functionality [9–15]. It seems that some technologies, although functional and designed with best intentions, are rejected because of their social

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Figure 1: (a) The typical hand of a nonambulatory person with DMD. There are already obvious joint contractures that create a bear claw shape for the hand. (b) A resting hand splint used commonly by people with DMD to preserve larger range of motion for the fingers and prevent contractures. (c) A novel active wearable robotic exoskeleton for people with DMD (SymbiHand [16,17]).

context, resulting in a lack of cosmetic appeal, social restriction or stigma.

In philosophy of technology, it has been proposed to call this problem the *dilemma of assistance and acceptance*: many people with disabilities need more technology than others to participate in society (assistance), but they also do not want to be “fixed” with technology or for their technology to add to the stigma they are already burdened with (acceptance) [18]. Balancing these two needs is not just a task of the individual users themselves but starts with decisions made by engineers and designers. Philosophy of technology can help understand the role of technology for their users and the importance of engineering decisions. Such decisions still often seem to be based on the problem-solving approach that engineering sciences subscribe to, thereby implicitly employing the individual model of disability. This model has been extensively criticized within disability studies, e.g., for its disregard of social factors and for patronizing disabled people into changing their bodies [19]. In spite of this substantial criticism, WRE researchers seem to implicitly use this model and, thereby, subscribe to an ableist conception of disability.

In general, such socio-philosophical considerations are largely absent from the engineering discourse [20]. Despite the significant amount of research done in the last 7 years [6–8,21] on WREs for people with DMD in the Netherlands, ethical and societal aspects of WREs for DMD are treated as an optional part of WRE research. The main focus of the WRE researchers’ work traditionally lies on the engineering developments [6,7] and safety (which is the case also for lower limb WREs [22]). As a result, the implementation of ethical and societal

considerations mainly relies on the will of the researchers [6,7] or external collaborations, e.g., [18]. Work in philosophy of technology has shown ethics not to be a limit to innovation but a possible source of it [23]. We suggest that considering the socio-philosophical perspective can increase the acceptability and acceptance of WREs. Although the problematization and solution to societal problems such as ableism and stigmatization, of course, should not and cannot be only the engineers’ tasks to solve, we aspire to demonstrate how an awareness of our socio-philosophical perspective can help engineers in their work.

In this article, Section 1 introduces DMD as a relevant case study for the development of WREs. In Section 2, we suggest the implementation of socio-philosophical perspectives, disability studies and philosophy of technology, in relation to WREs for DMD. In Section 3, we discuss how insights from these socio-philosophical perspectives in the development of WREs for DMD can lead to responsible design choices. We hope that this perspective can be partially extended to the development of WREs for other target populations as well.

2 Duchenne muscular dystrophy

Currently, most of the wearable assistive devices used for individuals with DMD are passive resting splints (Figure 1b) [24]. However, the benefits of active WREs are evident: they increase social participation and quality of life of people with DMD [25,26] with an immediate effect, unlike the alternative options (i.e., pharmaceuticals)

which target more long-term goals [4,6,24]. In some cases, WREs are already prescribed by occupational therapists [6,24].

In the previous years, DMD WRE research has received a lot of attention, mainly in the Netherlands and the United Kingdom but also in the United States of America, with the local Parent Organizations actively pursuing technical solutions [25,26,29–32]. This pursuit led to a variety of research projects that aimed at developing supportive technologies in the form of WREs for various body functions affected by the disease. In Europe, the *eNHANCE* is a Horizon 2020 project, with its main partners in the Netherlands and UK [33]. The main objective of this project is the development of WRE technologies for enhancing and training of the upper extremity motor function of individuals with stroke and DMD. The *Flexextension A-Gear* project [28] was a national Dutch project, which aimed for the development of an arm exoskeleton for individuals with DMD [6] (Figure 2a). For a person to be able to functionally exploit the arm movements, the movement of the hand and trunk is necessary to increase the reachable workspace, while the neck is needed to provide visual feedback of the arm's position. This issue was addressed by yet another national Dutch project called *Symbionics* [34]. The aim of this project was to develop WREs, for the dynamic and intentional assistance of the hand, the trunk and the neck of individuals with DMD and integrate it with the *Flexextension A-gear* to further enhance its functionality. A first passive trunk support prototype (Figure 2b) was developed and evaluated by Mahmood et al. [21], while an active one (Figure 2c) was developed and evaluated by Verros et al. [10]. Lastly an active WRE for the hand (Figure 1c) was developed and tested with one participant with DMD [7,17].

The development process of the *Symbionics* project is a good example to demonstrate how the current guidelines fail to accommodate the socio-ethical challenges of WREs, by mainly focusing on physical safety. For testing, the engineers needed to submit an application to the research ethics board of Delft University and undergo a safety inspection. This application focused on the description of the experiment and the motivation regarding the necessity of testing it with a specific number of people with DMD (in this case 1). The ethics application document was also accompanied by a data management plan, a letter of information and an informed consent form for the participants and finally the text that was used to recruit the participants (e-mail). Lastly, a safety inspection was needed because the device was about to be used in connection with human

subject research, so it falls under the regulations for electrical safety of medical devices according to IEC 60601-1 for Medical Electrical Equipment and Systems [35].¹ From this description, it becomes evident that medical and safety standards, as well as the participants' consent, are ensured, but wider societal and ethical implications are not included in the scope of the application. This focus is not unique for this specific case; ethics reviews at universities often only attend to "human subject research" and rarely take into account the actual use of a technology by an end user.

With this lack of regulation in mind, WREs for people with Duchenne are an ideal case study because these technologies are inherently conflicted: on the one hand, they can significantly help their users; and on the other hand, as we will show in the following paragraphs, they might contribute to ableism and stigmatization. As mentioned in the introduction, this conflict has been called the dilemma of assistance and acceptance [18]. It stems from the fact that WREs are highly visible and contribute to their users "standing out;" so unlike other assistive technologies, such as access ramps for wheelchair users and people pushing strollers, WREs can add to the stigma that disabled people are already burdened with. This holds especially true for individuals with DMD, for whom participation in society becomes increasingly dependent on technology due to the progressive and irreversible nature of the disease. In sum, WREs for people with DMD and the unique challenges they evoke are not covered by current guidelines, although such guidelines could help engineers and users immensely.

3 A socio-philosophical perspective

This section will introduce the theoretical perspectives for problematizing the stigmatization and ableism that currently often remain unaddressed in the engineering sciences. In the literature about disability studies and technology, the possible stigmatizing effect of assistive technologies is well-documented [37]. Wheelchair users have described the impression that others perceive the technology before themselves [38]. Stigma seems to come with any visible technology, not just wheelchairs but

¹ Recently a new ISO was released that is specific for medical robots (IEC 80601-2-78:2019 [36]) compared to the more generic ISO for medical devices [35].

Figure 2: The figure illustrates the results of various WREs developed for people with DMD. (a) A complete arm active WRE for people with DMD, adapted from [7] (Flextension A-Gear [28]). (b) A trunk and neck passive WRE for people with DMD, adapted from [21] (Symbionics 2.1 [27]). (c) An active trunk WRE for people with DMD, adapted from [21].

hearing aids, ventilators or exoskeletons. It can significantly impact a user's decision to use assistive technologies [39]. Understanding a stigma's cause can help identify strategies to minimize its negative effects.

Following sociologist Erving Goffman, a stigma is marking someone as a “less desirable kind” [40]. Such a “marking” presupposes a perceivable difference and a devaluation [41]: not only *different* but *worse*. The use of some technologies can constitute a mere perceivable difference, such as the use of a motorbike instead of a car, while the use of other technologies can constitute a *devalued* difference, such as described with assistive technologies. It is even possible for the same technology to be perceived as a mere difference or a devalued one: glasses, for example, are often devalued by peers if worn by children, while they usually constitute a mere difference in adulthood. Subsequently, the reason for stigmatization is located in someone's environment: the socio-cultural context decides whether using a technology makes the user a “less desirable kind.” In this sense, the underlying cause for the stigmatization of disability, its perception as “worse,” is ableism – prejudice against disabled people.

WREs, being clearly visible and often omitting perceivable mechanical noises, can contribute to such a stigma. At the same time, it is very difficult to make WREs more inconspicuous and quieter, meaning that the dilemma of assistance and acceptance becomes evident: WREs can contribute considerably to their users' participation in society (assistance), while they can also contribute to their stigmatization (nonacceptance).

Following the previous reasoning, it is important to note that this stigma is not inherent in the technology but stems from the socio-cultural context in which WREs are used. Changing the socio-cultural context would, therefore, be the most effective solution. However, ableism cannot be stopped overnight, and this article is concerned with what engineers can do through the power of design. Although WRE researchers might be aware of possible stigmatization and care about making improvements, they are often not asked for strategies to address this problem.

Ableism is not only inherent in the devaluing part of stigmatization, it is also present in the conceptual understanding of disability within the engineering sciences. The question of how disability can be described and conceptualized has been a long-standing theoretical and political discussion in disability studies. As mentioned before, the main task of engineering work lies in the development of a technical device. Working with a problem-solving mindset, engineers often use technology to “fix” missing body functions *they* perceive as a problem. This strategy, however, strongly resembles the ideas about technology within the individual model of disability, which has been conceptualized and criticized since the emergence of disability studies in the 1980s. The problematic individual (sometimes also called medical) model understands disability as an individual problem which can be identified and, ideally, fixed [42]. It locates the disability in the body of a disabled person only and focuses on the medical restoration of missing body functions. Narratives often

are either very negative, framing disabled people as experiencing a personal tragedy and deserving pity, or extremely positive, framing disabled people as managing their everyday life “despite” a disability. Because they are expected to perform less well in general, disabled people often get praised for otherwise ordinary accomplishments [40]. In both perspectives of the individual model, disability is perceived as “different from normal,” and their extraordinariness is highlighted in positive or negative ways.

As its focus lies on the individual coping with disabilities, the individual model asks for technology that restores body functions or at least supports disabled people individually [19]. It has been criticized for promoting a questionable notion of “normal” bodies; a “standard” that should be returned to through therapeutic means. According to disability studies scholars, such “objective” deficits were to be settled by doctors, which often did not allow for the discussion of the patients’ preferences [19]. In relation to that, the understanding of disabled people as dependent patients instead of autonomous persons constitutes another main criticism of the individual model [20]. Most disabled people want to be taken seriously as autonomous persons and reject paternalism and pity. In sum, the individual model can be called ableist – expressing discrimination and prejudice against disabled people. This criticism, which is well-established in disability studies, however, has not yet received much attention in the engineering sciences. Clearly, many engineers are dedicated to developing useful products and involve prospective users to a certain extent, but the theoretical basis coming from disability studies is often absent from engineering education and – so is the authors’ experience – is also absent from many engineer colleagues’ minds.

Constructive solutions for engineers could be derived from the social model of disability, which can be understood as the response by disability studies scholars to the individual model’s shortcomings [19]. By distinguishing between impairments (a missing body function) and disability (the impairment’s negative social effects), the social model does not locate the disability in a person’s body but in a person’s social environment (*ibid.*). In doing so, the responsibility for solving problems is shifted from the individual to society and government: the solution lies not in individual treatment but in the reduction of structural discrimination. Thus, technologies need to support the changes in the social environment of disabled people and not change disabled people’s bodies; the focus lies on

accessibility instead of therapy [20]. The concept of impairment has also been subject to criticism. The social model presents an impairment as a biological fact in terms of function. Yet, it has been argued that, instead, impairments need to be understood as shaped by social processes [43]. Following this argumentation, the social model unjustifiably separates body and culture and, thereby, neglects the sociology of the body [20,43]. The social model’s disregard of the body’s importance also leads to obscurities concerning assistive technologies. If a disability is not a physical fact but located in social conditions, technologies that are individually used and often working with bodies would not alleviate the effect of a disability. In sum, neither the individual nor the social model of disability seems suitable for the analysis of assistive technologies. As Anderberg points out:

The medical model oversimplifies disability as an individual characteristic and directs attention towards individual adjustments and means. The social model, on the other hand, directs attention towards ideological and political analysis, not towards practical everyday solutions for experienced functioning. [20]

As a result of the two models’ shortcomings, many hybrid models and extensions have been developed. Perhaps most prominently, the WHO uses a “biopsychosocial model” as the basis for their International Classification of Functioning, Disability and Health (ICF), which combines biological, individual and social factors [44]. Recently, it has been suggested to extend the social model of disability, taking into account that disabilities are socially and culturally constructed [45]. Such a “cultural model,” as proposed by disability studies scholar Anne Waldschmidt, “investigates how practices of (de-)normalization result in the social category we have come to call ‘disability’” [45]. Describing disability not as a given entity but as a “process, experience, situation, or event” [45], she argues that an adequate analysis must look at the institutional practices that lead to the construction of normality and deviance, health and functioning [45]. Yet, not only practices need to be considered also *material* things created and employed [45]. In this way, the cultural model of disability points to the importance of technology: if disability is what society creates with technologies and cultural practices, then the very definition of disability can be influenced by the way these technologies are designed and used.

This perspective is supported by insights from Philosophy of Technology and Science and Technology Studies, in which it has been established that technologies cannot be understood as neutral tools [19,38]. On

the contrary, technologies have been ascribed a fundamental role for individuals and society, for example by mediation theory, which analyses the role of technology in human-world relations [46]. We often do not directly perceive or interact with the world but do so via technology. As a result, technologies mediate human actions and perceptions; they are not neutral intermediaries but active mediators [46]. Hence, they influence how people can live their lives and can contribute to stigmatization, although such effects are not intended by developers [47]. This view is compatible with the cultural model of disability: technologies and their use can shape the perception of disabled people and disability itself. By taking this insight seriously, not only can the negative effects of WREs be explained, but first steps can also be taken toward a more acceptable design and use of WREs.

4 Implications for the development of WREs

From the problems drafted in the previous section, it becomes clear that good development and design of WREs should avoid stigmatization and ableism. Possible strategies for doing so can be derived from the previously expressed criticisms.

Taking the criticism of the individual model seriously, the autonomy of disabled people needs to be acknowledged more and prejudice against disabled people needs to be reduced. A more equal relationship between user and developer already reduces the probability of ableism and medical paternalism. If users and their preferences are taken seriously, the product will likely be a patient-desired solution to a problem expressed by patients instead of a medically imposed solution to a medically perceived problem. Concretely, WRE engineers should ensure that the prospective users have expressed the desire for their product and not assume that any deviation from a “normal” body constitutes a problem in need of a technological solution. This could be ensured, for example, by collaborating with patient organizations. In the *Flexension A-Gear* project [32], for instance, the DPP had expressed the desire for arm and hand support by cofunding the project. Furthermore, users’ autonomy can be acknowledged by asking for input during the design process and by providing different design choices.

Hence, a key strategy is the inclusion of potential users throughout the complete development process.

This strategy is supported by recent studies on the acceptance of WREs, which suggest the need for the early involvement of users in the design process and observe that such involvement is becoming a common practice [48]. This idea is also very much present in the concept of Human- or User-Centered Design (UCD) [49]. UCD is based on the active involvement of potential users in order to improve the understanding of users and lead to solutions that successfully reflect their needs. It is already a prerequisite for many European funding bodies, e.g., the EU Horizon2020 program [50], and the Dutch NWO [51]. Recently, UCD was also defined in ISO 13407 and the associated technical report, ISO TR 18529 [49]. For lower limb WREs, the need for UCD was highlighted, and it was proposed that the user with a disability should be in the center of the innovation process to improve the WREs design quality [22]. However, the acknowledgment of the problem in academic literature has not led to implementation in current engineering practices: while most UCD approaches acknowledge the fact that the human is in control of the device, they do not include the users in the thinking process [52,53]. There is only some recent evidence of active participation of the users in the design process of WREs [7,54–56]. In these cases, UCD was applied by employing focus groups, meetings with experts, occupational therapists, doctors, engineers and individuals with DMD, in order to improve the WRE design process [6,7].

The involvement of users is important not just for research that results in commercial products but also for proof-of-concept designs. Even such early designs may already express perspectives on disability that are continuously expressed in the later product and will make it hard to adapt to new insights coming from the users. Although it is challenging to address issues such as modularity and customization early on, there are design tools for such early stages, e.g., quality function deployment (QFD). QFD is a commonly used design engineering tool that translates user requirements to technical requirements early in the design phase and ensures that those are carried out throughout the complete development process [57,58].

Through active user participation, developers will also be pointed to the fact that individuals with DMD are probably already investing time and effort in *other* research projects, which may lead to user burden. Yet, despite their effort, individuals with DMD still have minimal access to the data from this research. This problem points to the limitation that user participation not only *needs* to happen, but it needs to happen *in a responsible way*. A positive example for such responsible

user participation are efforts by the World Duchenne Organization (WDO), the Duchenne Map and the Duchenne community advisory board to create the Duchenne Data Foundation (DDF). This initiative aims to make people with DMD owners of their own research data and promote research and patient-researcher collaborations [59,60]. This initiative will also create a structured data platform, which reduces the burden for people with DMD and increases the data pool of studies available to researchers and thereby contributes to solving the problem of having too few study participants [6,7,10]. Hence, responsible user participation can benefit both user and researcher.

Autonomy and choices of users are not only important throughout development, but also concern the end product. Modular WRE design can provide a set of choices to users that may allow them to customize their own device to their individual needs and preferences. These are not limited to functionality but can also include aesthetic choices as well as the visibility of the technology. A common strategy is to make WREs as inconspicuous as possible to reduce stigma.

As explained before, the dilemma of assistance and acceptance demonstrates how stigmatization cannot be entirely avoided due to the ever-present visibility of WREs. However, the cultural model of disability shows that technologies can shape what “disabled” means; and mediation theory shows that technologies shape perceptions and actions. Considering these insights, an alternative strategy could be pursued with good design: what if WREs could identify their users as disabled but, at the same time, make disability be perceived more positively? This effect has been described with other technologies before; for example, with a new wheelchair:

Even though I’ve had a disability life, little did I know that the new chair would really cause people to stare – but more out of amazement than pity. The chair itself is the optimum in high-tech. [61]

Coming back to Goffmann’s description of stigma in Section 3, such technologies would make their user not a “less desirable kind” or let them be perceived as neutrally different (such as the adult glasses example), they might be perceived as a “desirable kind” instead. An aesthetic WRE design could cause people to notice the technology – in an enthusiastic way. Instead of hiding technology away, as with skin-colored materials, one could develop assertive, self-confident designs. Custom designs have been successful in the field of

prosthetics, where companies aim for individualized, colorful solutions that change the perception of prostheses [62]. However, it should also be acknowledged that many users, who are usually less vocal about their preferences, do not wish to stand out and prefer inconspicuous designs instead. Such preferences once again highlight the fact that disabled people are a heterogeneous group with different attitudes and needs. Modular design could help users to make such aesthetic and visibility choices according to their preferences; not only once but according to their changing preferences as well. The actual decision if a new technology should be modular/customizable is a core decision that needs to be taken early on and is usually dictated by the user needs.

Despite the challenges of such an approach (mainly cost-effectiveness), rapid prototyping techniques can revolutionize mass customization and reduce related costs [63], while enabling the developers to design custom WREs. While modular design is not new in the context of WREs, it is often concerned with adaptability in different environment-related scenarios (walking vs. running or going upstairs, etc.) [64,65] rather than aesthetics and stigma. We suggest adjusting the scope of modular design in order to address user needs that extend beyond functionality and comfort.

5 Discussion and conclusions

In the beginning of this article, we pointed out that current regulations on WREs developed for people with DMD are lacking guidance for the reflection on wider ethical and social implications of WREs. We argued that at least two perspectives are overlooked, namely, (1) the problematization of the ableism inherent in the often still applied individual model of disability and (2) the stigmatization stemming from the visibility of the technology. Philosophy of technology and disability studies explain how WREs shape their users’ perceptions and actions, and how WREs shape what it means to be “disabled.” From these perspectives, we deduced recommendations for the development of WREs: the involvement of patient organizations and a participatory approach to design can help reduce ableist ideas, and the provision of modular design and choices can help reduce the stigma attached to WREs.

We hope that our recommendations help engineers reflect on the role their work plays for their users and would like to advocate for such reflection to become,

where it is not yet, part of engineering education. Such education could include, besides our socio-philosophical perspective: communication and soft skills; designing for the users' experience [58]; the importance of the long-term patient experience [66]; usability testing for managing user's expectations, beliefs and emotions [22]; and long-term experience concepts [67]. Other ways to sensitize developers can include measures like including patient organizations and health-care providers (as exemplified by the *Flexension A-Gear* and *Symbionics* projects [32,33]) and collaborating with institutes, or standardizing frameworks for appropriate user inclusion in the development of medical technologies.

Our recommendations are, to a certain extent, also applicable to other WREs outside the context of DMD. The involvement of patient groups and the provision of choices are also valuable means to achieve better WREs in general. However, our solutions do cater to some specifics of the Duchenne case: due to the irreversibility of the disease, the WREs will be used permanently and cannot be exchanged easily. That underlines the impact of the technologies on users' lives and makes the provision of (daily) choices more important. Furthermore, the population of people with DMD are generally positive toward new technologies by funding research projects [32,33], which fit the suggestion for more assertive designs. In other cases, patients might prefer more inconspicuous designs or be against the idea of WREs in the first place. Of course, not all patients with the same disease have the same preferences, which underlines again our plea for individual choices.

A limitation of this article is the lack of direct involvement of users and patients in our study. Although the article could have benefited from direct quotes of people with DMD, this article was not meant to be an interview study but a theoretical reflection with implications for practice. Our analysis is based on literature from engineering, disability studies and philosophy, including previous patient/user studies (e.g., [38,68]) as well as the authors' continuous contact with people with DMD. Therefore, we do think that the user perspective is reflected sufficiently. We also realize that our small list of recommendations is not exhaustive. We aimed for the inclusion of a socio-philosophical perspective, not for the development of a systematic framework. Still, we hope that our recommendations can contribute to better practice around the development of WREs and will stimulate a larger discussion on the ethical and societal implications of WREs.

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