Adolescent ambivalence about diabetes technology—The Janus faces of automated care

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Abstract
The Janus face metaphor approach highlights that a technology may simultaneously have two opposite faces or properties with unforeseen paradoxes within human-technology interaction. Suboptimal acceptance and clinical outcomes are sometimes seen in adolescents who use diabetes-related technologies. A traditional linear techno-determinist model of technology use would ascribe these unintended outcomes to suboptimal technology, suboptimal patient behavior, or suboptimal outcome measures. This paradigm has demonstratively not been successful at universally improving clinical outcomes over the last two decades. Alternatively, the Janus face metaphor moves away from a linear techno-determinist model and focuses on the dynamic interaction of the human condition and technology. Specifically, it can be used to understand variance in adoption or successful use of diabetes-related technology and to retrospectively understand suboptimal outcomes. The Janus face metaphor also allows for a prospective exploration of potential impacts of diabetes-related technology by patients, families, and their doctors so as to anticipate and minimize potential subsequent tensions.

KEYWORDS
adolescents, diabetes, technology, uptake

1 | INTRODUCTION

In this digital age we increasingly turn to scientific and technological solutions for the adverse challenges of life. Technological panaceas though are not neutral or without countervailing impacts of their own. Technologies have emergent characteristics and properties (“affordances”) that play their part in our interactions with life-challenges. These affordances are specifically designed to meet and to mitigate the challenges we face, and they may do this to varying degrees. However, there may also be perverse, ironic or paradoxical impacts of technologies. First, the benefits of technologies for one individual may be inconsistent or have unwanted and unforeseen consequences. Second, the technological solution may change the context of the challenge and the agency or capabilities of the person challenged, thus changing the nature of the problem itself. In other words, the affordances of a particular technology may ameliorate and at the same time exacerbate the challenge, and change the nature of the issue at hand.1–3

Currently, nearly three decades after the findings of the Diabetes Control and Complication Trial (DCCT) were published,4 many adolescent patients still struggle to achieve either a current consensus target HbA1C or even the HbA1C levels that were achieved in the DCCT.5–7 At the time of publication of the DCCT results, an accompanying editorial noted the highly selective nature of the DCCT cohort and asked
the following question: “Who among the many patients with diabetes is likely to benefit from intensive therapy? Intensive therapy now encompasses an increasing array of technologies and interventions: insulin delivery and glucose detection devices, insulin types, diabetes education strategies, and psychological support strategies and the notion of matching the patient to the therapy remains pertinent. How do adolescent patients and their health care providers best navigate through the complex array of therapeutic options to achieve optimal health outcomes?

The frequently heard cry for more and greater access to technology to achieve better health outcomes assumes a somewhat uncritical view of the published outcome data. Over the last two decades there has been an exponential increase in the use of diabetes-related technology (defined here as automated or semi-automated detection and treatment solutions) in pediatric and adolescent patients. While some groups have shown improved outcomes in metabolic markers, this is not true of all populations. Indeed, despite increased technology use, metabolic control has deteriorated in some instances. These variable responses in outcomes speak to variations in how the technology is used and how acceptable the technology is to various groups. Why would one population of adolescents embrace and excel in the use of technology yet another struggle? The obvious suspects of literacy, numeracy, and socioeconomic factors would not seem to be applicable when one is comparing population registries from countries with similarly developed health care systems in the examples cited above. Variable cultural and individual acceptance of the affordances of diabetes-related technology might instead be determinative of outcome.

The Janus face metaphor has been previously used to describe how people adapt to the various affordances offered by technological solutions. In particular, the Janus face perspective highlights how some affordances may simultaneously have opposite properties and thus create inherent tensions or paradoxes for adopters of technological solutions. In the context of type 1 diabetes in adolescence, these tensions occur against a variable background of sense of self and readiness or ability to change or embrace diabetes-related technology. The purpose of this commentary is to explore tensions and paradoxes created by the Janus faced affordances of diabetes-related technology and consider how these might influence the use of such technology in adolescents with type 1 diabetes.

2 | THE JANUS FACE METAPHOR AND NOTIONS OF PARADOXICAL PROPERTIES AND AFFORDANCE TENSION

Metaphors are useful rhetorical instruments, not just for communicating a phenomenon, but also for generating analysis and understanding of the phenomenon in question. The metaphor of the Janus face relates to a well-known Roman god held to be responsible for transitions, for beginnings and endings, births and deaths, war and peace, leaving and arriving, the sacred and the profane. Janus is usually depicted as having two faces, and with these two faces, he is both blessed and cursed. Janus is blessed to be arriving, yet in the same movement, is always leaving. Janus simultaneously faces forwards and backwards (Figure 1). This is not a choice, it is his very nature.

The Janus face metaphor is used here in an analysis which focuses on the paradoxical or perverse impacts we often observe when trying to understand why a given technology is not achieving what is was designed to achieve. Examples of the Janus face metaphor include traffic congestion often becoming worse when we build more roads; air-conditioning systems creating a hotter global environment as well as a cooler local environment; antibiotics killing bacteria but potentially creating more resistant pathogens; and mobile communications devices making us equally close, but also equally distant. When the use of diabetes-related technologies fails to achieve desired clinical outcomes, the Janus face metaphor is again useful to deploy. A traditional linear “techno-determinist” approach (defined here as a unidimensional model of outcome being determined solely by the properties of the technology) assumes that treatment failure results from diabetes-related technologies failing to perform as designed, patients failing to perform as instructed or incorrectly defined clinical outcomes (Figure 2). The corollary of this is that clinical solutions are framed in terms of “better technologies,” “better patients,” or “redefining desired outcomes.” As has been previously noted, this linear approach has failed to transform clinical outcomes in pediatric diabetes over the last 10–20 years. The Janus face metaphor on the other hand, moves away from a linear techno-determinist model and focuses on the dynamic interaction of the human condition and technology. Specifically, the Janus face metaphor approach highlights unforeseen paradoxes, contrariness and ironies within this interaction. These unanticipated properties are as much an “affordance” of the technologies, and determinative of outcome, as the programmed and anticipated properties.
To apply the Janus face metaphor to the case of technologies for diabetes one must therefore look not just at the technology and assess the extent to which its pre-determined functions are executed, but instead look at the technology’s relationship to its user, and assessing the emergence of new outcomes afforded by that relationship. The effects of technologies for diabetes are not reducible to linear functions, but are emergent in a context where:

a. The performance of the diabetes technologies give rise to multiple possibilities for action, at least some of which pull in opposite directions toward contrasting outcomes (Figure 3).
b. These contrasting outcomes may occur on the same axis of analysis.
c. Importantly, these contrasting outcomes or implications are not a result of a failure in the technology, or a failure on the part of the user of the technology, but are co-dependent and co-productive, and are intrinsic to the operation of the system.

These points imply that the emergence of possibilities when certain diabetes-related technologies are interacting with certain users in certain contexts is not determined by the technology, user or context. Put simply, the addition of diabetes technologies to a person with diabetes, does not result in the same person in the same context, plus technology. The person with diabetes has properties such as personal characteristics, capacities and desires, and the technologies impact on these. The relations are complicated by many influences in the context of the technology and user. In other words:

... technology does not answer this or that question, satisfy this or that demand, or extend this or that capacity. Rather, technology works at a more fundamental level; it enframes the world such that the question is changed along with the answer, the need is changed along with its gratification, and direction is changed along with the mechanism. The calculator, the word processor, are not more effective, efficient or convivial methods of doing mathematics or writing – they change what it is to do mathematics and to write... (Arnold et al., p. 236)

In this way all technology, including diabetes-related technology, operates at a metaphysical level not just an instrumental level. The paradoxes, ironies, and contrariness of technology affordances can generate tension. This affordance tension may in turn lead to ambivalence or a lack of acceptance which may ultimately undermine adoption and effective use by the technology user.

When diabetes-related technology first arrived in the form of insulin pumps, their novel performances were rapidly observed by clinicians. One eminent colleague quipped in a presentation on insulin pumps at the European Society for Pediatric Endocrinology in 2004 that it was as though patients using pumps were “made of glass.” They had become transparent. There were no more secrets as most of the adolescent’s diabetes related behaviors had been automatically recorded and could readily be seen in the pump download. The presenter commented on how useful this was for the clinician but also how confronting it was for many of his adolescent patients (the pump faces both ways). The use of diabetes-related technology profoundly changed the dynamic of the follow-up clinical appointment. Since that time, technological “solutions” have provided more information on patient behavior in increasingly granular and, some might argue,
As technology advanced, when technology is in the case of the https://openaps.org/what-is-Affordance tensions associated with diabetes-related technology. In some respects this seemingly contrasting approach of Thus while the technology may assist If their adolescent child adopts Diabetes-related technologies paradox-This fragile transfer of trust can be either Arguably, the ultimate man-From a parental perspective, the transition to independence is one of the major developmental tasks of adolescence. In chronic disease this transition can be more problematic, whereby the burdens imposed by that disease create tensions and difficulties in forward progress. When technology is overlayed, the use of that technology may make the adolescent less dependent on their adult care givers, but paradoxically more dependent on the technology itself. Thus while the technology may assist the adolescent to “leave the parental nest;” it does not necessarily foster diabetes-related independence, rather it may instead simply foster a transfer of dependence. From a parental perspective, the process of their child’s independence implicitly involves trust. In a non-diabetes context this trust revolves around the adolescent being mature enough to make good choices in life. In the diabetes context which is often perceived as ever-threatening, the trust dilemma for parents is considerably heightened. If their adolescent child adopts a diabetes-related technology option, parents now have to trust both their adolescent’s choices and the “black box” of an insulin-delivery algorithm or glycaemia alarm system. Parents who have been caring for their child’s diabetes for many years in an experientially informed and nuanced manner, now face the quandary of new having to transfer trust to new care-givers, their adolescent child and opaque technology systems. This fragile transfer of trust can be either supported by good outcomes or alternatively undermined by a suboptimal responses to technology usage by their adolescent offspring or poor technology performance (e.g., inaccurate CGM readings, repeated false alarms, performance issues with consumables such as glucose sensors and pump cannulae, etc). Repeated technical failure experiences are not uncommon and can lead to frustration from the adolescent trying to achieve independence or fear and frustration by the parent trying to encourage independence. Paradoxically, the very technology that might assist in independence also has affor-dances that may impede independence. Arguably, the ultimate man-festation of this trust dilemma is seen in the consumer driven Open Artificial Pancreas System Project (https://openaps.org/what-is-openaps/), the foundations of which are built on transparent, patient controlled technology systems.

Another paradox relates to information flow. Having more diabetes data upon which to base decisions may be a useful thing for some ado-lescents. Yet in others a continual data stream may become a form of white noise and mitigate against engagement with and the use of those data. The diabetes data stream may be linked to alarms that paradoxi-cally either “encourage” or “coerce” adolescent patients to engage with the technology to facilitate a treatment outcome. In the case of the latter, the adolescent experience of a cajoling parent may be transposed by an alarming/cajoling machine. The alignment of technology in addressing an adolescent’s perceived needs is determinative in their use of it and response to it. Diabetes-related technologies paradoxically provide both immediate and delayed or summary data. In the context of day-to-day life, the emphasis is on the immediate data with actions having to be taken in response to glycemic perturbations to prevent clinical deterioration and calculations made around prandial insulin dosages. However, best outcomes are achieved if there is also a strategic retrospective assessment of trends and repeated outcomes over time. In some respects this seemingly contrasting approach of immediate and delayed responses is true of all diabetes management regimens, but the dominance of real-time decision making afforded by diabetes-related technology, extends this paradox considerably.

Finally, most adolescents wish to blend in with their peer group and resist badges or restrictions that would visibly identify them as being different. Insulin pumps theoretically do allow for less planned, more spontaneous activity allowing diabetic adolescents to blend in behaviorally. Yet insulin pumps and other devices are simultane-ously present and visible, providing a “badge” that is a visual reminder that diabetic adolescents are “different.”
The uptake and acceptance of some technologies such as smart phones and sharing of personal information on digital media appear to be universal among adolescents. For the most part, these technologies facilitate knowledge access, increase ease of transactions and enhance peer group interaction. Their unifying feature is that they are seemingly controlled by the adolescent in what some have termed a “participatory surveillance” paradigm of mutuality, empowerment and sharing. The performance paradoxes of such technologies are accepted because the technology performance changes the nature of the affordance in a way that is accepted and valued by the user (e.g., with a mobile phone, one is not either distant or connected, one can simultaneously be both). On the other hand, technologies that manifestly control adolescent behavior (even if it is in the context of health promotion) appear to be less universally accepted. In cultures that vary in individuality over conformity the paradoxical affordances associated with diabetes-related technology may have varying impacts. For example, adolescents who use “conforming” are less troubled by a lack of control, less concerned about the need for independence, less troubled by adherence coercion and less concerned about badges of illness. On the other hand, adolescents from cultures that emphasize individuality and freedom of choice may be more likely to respond negatively to technologies that automate control, coercion, and dependence. The compact of accepting technology altered affordances might be perceived to be more or less conflicted depending upon contextual cultural norms.

5 | RESOLUTION OR CONTINUANCE OF AFFORDANCE TENSION?

Technology, adolescents and contexts are continuously changing. In order of frequency, the physical and emotional changes of adolescence (monthly) are usually more rapid than iterative technology change (2–3 yearly) which is again more rapid than fluxes in social norms (generational). Psychological and social theory would indicate that in adolescence, individual and social norm changes will have the greatest impact. However, the impact of technology upon the environment (e.g., social media usage) should not be underestimated. Given this state of dynamic flux one would also expect to see associated changes in the affordance tension ascribed to the interplay of device, patient and environment. Affordance tension may resolve, continue, or increase according to individual circumstance. For example, in a diabetes context tensions around data privacy versus data visibility may change according to the adolescent’s changing desire for privacy (less or more), the type of data that is shared (summarized or granular), the people with whom it is shared (parents or partners), the reasons why it is shared (requirement for licensing, insurance or occupational fitness) and the acceptance of the adolescent/young adult’s peer group (social peers or work colleagues). The consequence of this ever changing dynamic is that technological solutions are far from a “set and forget” proposition. Simply put, the perceived pros and cons of and acceptance of technology use by adolescents and emerging young adults can vary over time and clinicians should be prepared to discuss changing levels of readiness for change or acceptance of the status quo.

6 | INCORPORATING THE JANUS FACE METAPHOR INTO CLINICAL PRACTICE

Affordance tensions that might impact upon individual patient engagement need to be acknowledged as part of critical agency of any adolescent engaged in decisions around technology usage. All the more so when adolescents have experienced living with diabetes for some time and may have developed significant preferences for how they should manage their diabetes. Whereas there may be strongly held views by either clinicians or parents, about the likely benefits that will ensue from introducing new technology, any such plan needs full and honest discussion with the young person themself.

The principles that underpin communication approaches for facilitating behavior change, such as motivational interviewing, provide a useful framework for embarking on such discussions. These discussions should start by trying to understand the likely benefits and challenges (pros and cons) from the young person’s viewpoint of using the technology; in other words, a review of the Janus faces or affordance tensions of the technology concerned. It is important to recognize and acknowledge that a young person may have a different perspective to their parents or the healthcare professionals on these tensions. For example, as mentioned above, the greater transparency afforded by continuous glucose monitoring may be deemed unacceptably intrusive from an adolescent’s perspective and concerns such as these should be discussed in full, using an empathic and non-judgmental approach which recognizes the young person’s autonomy and agency. It is equally important for treating teams to be aware of their own heuristics and biases and how these may impact on discussion of the potential advantages and disadvantages of various technologies.

The next step in communication, should be to identify the importance that the young person places on addressing this aspect of care and their associated confidence that they can engage with the technology in question, assessing their so-called “readiness to change.” From the perspective of the young person, if there is little importance attached to improving the aspect of care in question, it is unlikely that there will be much motivation to incorporate the technology in question and make a success of its use. In such circumstances, careers may be better advised to delay using the new technology and to initially focus upon why the issue in question is of little concern to the young person.

If the young person is still engaged with the idea of changing their self-management then the discussions need to review their confidence that they can incorporate the new technology into their care package. It is critical to finish by drawing up an agreed plan of action, including identifying training requirements and any need for ongoing support. Ideally, the young person should be in charge of decisions about both when and how the impact of the technology be judged, recognizing that from their perspective, benefit may not be entirely focused on blood glucose-related outcomes. It is also important, that
the possibility of reversing the decision to introduce the new technology at some point in the future is allowed for, should the experience of using the technology prove counter-productive from the young person’s perspective. Critically, the young person themselves should be in charge of agreeing this plan of action, as this is more likely to ensure their engagement with the process. Interestingly in a trial of motivational interviewing communication, those young people with the greatest worry and lowest satisfaction with their diabetes care, experienced the greatest glycemic improvement. This affirms the notion, that selection of those with the greatest pre-existing concerns about their self-care and greatest “readiness to change” in their patterns of thinking, will likely benefit most from behavior change techniques.

However, when technological interventions are considered for the newly diagnosed who have no previous experience of diabetes self-care, the scenario is slightly different. In these circumstances, young people and their families are likely to look to health-care professionals for advice on how best to manage their diabetes, given their likely previous lack of knowledge and experience. This may partly explain why the impact of interventions such as insulin pumps at diagnosis has proved less beneficial than suggested by some large registry studies. Even at diagnosis, there was a high rate of refusal of the newly diagnosed to take part in a technology trial and a high dropout rate in those who were not randomized to their preferred treatment. This suggests that even in those with no prior experience of managing their diabetes, careful patient selection is still important to identify those most likely to benefit from technological support.

7 | CONCLUSION

Outcomes in type 1 diabetes remain suboptimal for many if not most adolescents. The addition of diabetes-related technology to self-care over the last two decades has been associated with variable improvements or deterioration in different cohorts. Understandably clinicians have looked for reasons and a deeper understanding of why this is occurring. The traditional linear techno-determinist model implies that the simple application of technology to a patient should lead to an improved outcome and that if this outcome is not achieved there must be a problem somewhere along the clinical line of cause and effect. This may lead to a blame paradigm where bad technology, bad patients or bad measures are variably blamed for bad outcomes. The blame paradigm eschews that in suboptimal outcome situations the technology, the patient or the outcome measure are the things that “need to change.” This paradigm though, has demonstratively not been successful at universally improving clinical outcomes after many years of experience.

Clinicians need to understand that human use of technological solutions in particular contexts may generate simultaneous affordances which may be paradoxical. Exploration of these effects requires health care providers to think beyond traditional clinical paradigms. Accordingly, further research enquiry in this area of human interaction with diabetes health care technology requires broader expertise that should encompass consumers, engineers, clinicians, psychologists, and philosophers. The Janus face metaphor describes the phenomenon of paradoxical affordances and the inherent accompanying tension. It can be used to understand variance in adoption or successful use of diabetes-related technology. In addition to retrospectively understanding suboptimal outcomes, use of the Janus face metaphor allows for a prospective exploration of potential impacts of diabetes-related technology by patients, families and their doctors so as to anticipate and minimize potential subsequent tensions. This in turn will inform a deeper understanding of readiness for change by the adolescent and whether it is timely to introduce diabetes-related technology into their overall self-care package.

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