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Abstract

This paper uses a socio-material approach, social practice theory, to provide new insights into the self-management of chronic illness. It demonstrates how this theory can bridge arguments about the respective roles of social and individual influences, and how it can foreground an oft-overlooked aspect of the issue – the demands of self-care technologies and consequences for participation in social life. Drawing on interviews and focus-groups with 25 young type-1 diabetes outpatients in London, UK, the study points to the conflicts that occur when disease management technologies compete for time and space with the social practices of everyday life, and when self-care tasks threaten to interrupt the flow of social life and make people feel ‘left behind’. The paper concludes that young people are disabled by the contingent position of self-care activities in daily life, which oblige them to compromise either their physical health or their immersion in the social world. This disabling effect would be mitigated if social practices were reorganised to make them more amenable to the timespace requirements of disease management. A social practice theory lens can help throw light onto this issue and make a valuable contribution to the study of the self-management of chronic illness.

Introduction

Although the availability of mobile illness management technologies has transformed the opportunities open to people with chronic illness, it has also introduced new difficulties. Thanks to these technologies, people with chronic illness have less need to physically distance themselves from the social activities of their peers. However, the insertion of self-care tasks into the temporal-spatial structures of social activities, like the use of ‘convenient’ technologies in other domains (Shove et al. 2012: 170), increase the need to ‘shift and juggle’ conflicting social and material demands. This exacerbates the challenge of coordinating everyday life. This paper uses social practice theory (henceforth ‘practice theory’) to understand how this challenge leads to the omission and delay of disease management tasks.

In practice theory, behaviours are considered to be the result of bundles of socially organised activity known as *social practices* – and it is these bundles of activity, rather than individuals or society, that are the primary unit of investigation. Although it is being championed in public health research (Blue et al. 2016, Meier et al. 2018) practice theory remains underexploited in health research generally (Maller 2015) and appears not to have previously been applied to the management of chronic illness.

The use of practice theory has a number of advantages for the study of chronic illness management. The first advantage is that it allows analysts to consider both socially determined aspects of behaviour and individual agency (Maller 2015). Although practice *entities* are said to be socially determined, it is argued in the practice theory literature that individuals retain some freedom in how they *perform* practices (Schatzki 1996). This view allows the unification of two strands in the literature on chronic illness (Bury 2010): that which focusses on social context (e.g. Pinder 1988, Strauss et al. 1984) and that which focusses on technical competence – e.g. the ability to change a

colostomy bag (Kelly 1992) or gauge the oxygen requirements of physical tasks (Fagerhaugh 1973). This dual focus of practice theory helps avoid the 'personal tragedy' model that is said to have dominated medical sociology (Scambler 2006, 2009). It also facilitates the exploration of the uncomfortable space between agency and structure, and between the successful and unsuccessful performance of a practice – both key theoretical foci of this paper.

A second advantage of practice theory is that it obliges analysts to focus on a broad range of the influences on illness management behaviour. Social practices are conceived as comprising a number of elements, each of which points to a different type of influence on behaviour. Although there is some dissent about what these elements are, four are fairly typical: meanings, skills, material arrangements and social rules. These might cover, for example, the *meanings* of 'health' and 'diabetic'; the *skills* necessary to adjust medication doses; the affordances and demands of *materials* such as medical equipment, and the *rules* of behaviour at mealtimes.

Of these four elements of a social practice, elements, skills, meanings and materials are already widely addressed in the literature on chronic illness (e.g. Fagerhaugh 1973, West 1976, Strauss et al. 1984, Kelleher 1988, Morgan 1988, Pinder 1988, Kelly 1992) while social rules have suffered relative neglect. This is perhaps because much self-care was, until recently, confined to the home or hospital (e.g. the test-tubes, methylated spirits and glass syringes once required by people with type-1 diabetes). Hence, although it intruded upon the social practices of home life (Strauss et al. 1984) self-care less often impacted upon non-domestic practices. This study focusses on the difficulties encountered when the portability of contemporary self-care technologies cause such impacts to be experienced more often – e.g. on practices such as school-break-times, eating-out and playing-with-friends.

Another way in which this study complements previous research is by focussing on the influence of material elements of self-care technologies when they are inserted into other social practices. As with the issue of stigma, previous research has done a great deal to reveal the social challenges associated with using self-care technologies. Amongst these, the implications for identity (West 1976, Williams 2000, Browne et al. 2014) are still important today, as before. However, we argue that the increasing portability of self-care technologies (e.g. wallet-sized blood glucose meters and insulin 'pens') reduces the salience of research (e.g. Pinder 1990, Kelleher 1988, Morgan 1988) into the spatial exclusion of users from other social practices. We use practice theory to reveal how, although portable technologies facilitate participation in a fuller range of social practices, by preventing adherence to the rules and timespace demands of these practices, they limit the extent of this participation and sometimes cause users to feel left behind.

In order to consider the difficulties involved in interweaving illness management with everyday life, we draw on formulations of social practices that emphasise aspects of time and space. Schatzki (2009: 41) argues that the infrastructure of the social world consists of sets of practices that, being "tied" together, require coordination in time and space. This need for coordination has implications for practice prioritisation. People are expected to prioritise practices that need social coordination (Southerton 2006) and to relegate to "empty slots" tasks that do not need such coordination. This view of the social organisation of time allocation casts a different light on the availability of time for self-care tasks. Previously, it has been argued that shortages of time oblige

people to choose between managing their illness and participating in social life (Fagerhaugh 1973, Strauss et al. 1984, Morgan 1988). The practice theory perspective suggests that even when there is no absolute shortage of time, the availability of time for self-care activities is restricted by the priority access given to collective practices and by the rules that govern such practices.

The paper takes type-1 diabetes amongst adolescents as its case-study. Type-1 diabetes (henceforth 'type-1') is of particular public policy significance because of its increasing prevalence. Its global prevalence is increasing at 2-5% per annum (Silink 2002, Maahs et al. 2010) – a rate that could double in the next decade (Atkinson et al. 2014). Already, 0.3% of the world's children and young people have the disease (IDF 2013), including 129,000 in Europe and 109,000 in North America (Liese et al. 2006, Patterson et al. 2014). The clinical management of this condition is important because of the consequences of poor management for individuals and levels of health service demand. Type-1 is most commonly diagnosed during adolescence, which is also the life-stage during which clinical outcomes are at their worst (RCPCH 2012).

Unlike type-2 diabetes, which is associated with life-style (Narayan *et al.* 2000), type-1 develops when a faulty auto-immune system destroys the body's pancreatic insulin-producing cells (Atkinson et al. 2014). If not managed properly, this incapacity of the body to control levels of sugar in the blood causes fatigue, confusion, loss of concentration, hospitalisation and, in the longer-term, impacts such as vision loss and peripheral neuropathy (Plotnick and Henderson 1998, Cox et al. 2002, Lau et al. 2004). The loss of insulin-producing cells can be substituted for by the administration of manufactured insulin via infusion or injection. However, in order to administer appropriate doses, people with type-1 need to be able to "think like a pancreas" (Plotnick and Henderson 1998: 79). This represents a significant challenge, for the calculation of an appropriate insulin dose depends on the extent of recent and anticipated exertion, hormone levels, carbohydrate intake and other factors (Thompson 2012). Some aid is provided by technologies such as infusion pumps, injection 'pens' and blood glucose monitors, but self-care nevertheless constitutes a significant cognitive burden and demand on time (Wysocki 2006). Hence, although type-1 presents no innate physiological barrier to participation in everyday life, the reflection and calculation that is needed to manage the disease inevitably distracts from other activities (Hinder and Greenhalgh 2012).

There are no fixed prescriptions for the frequency with which care tasks should be undertaken. Although it is advised that routine blood glucose monitoring should be performed "several times a day" (Plotnick and Henderson 1998: 8) additional testing is needed around physical exertion or when there are signs of blood-sugar levels being high (Estridge and Davies 1996). Similarly, the routine 2-4 daily injections are supplemented by additional ad-hoc doses when blood-sugar levels are high or extra carbohydrate is consumed (Jeandidier *et al.* 2008). Neither blood tests nor injections are conventionally done in public, and blood tests require being stationary and having access to a surface on which to rest equipment.

We add to existing research on young people (e.g. Gabe et al. 2002) by drawing on concepts and approaches from the 'new' sociology of childhood (Brady et al. 2015, Mayall 1998) and focussing on the negotiation of 'everyday situated interaction[s]' (Scott et al. 1998: 692) in adolescence in the relationship between the performance of daily life and the management of type-1 (Mielewczyk and Willig 2007). We argue that

the demands of type-1 self-care technologies cause the disarticulation of young people from social practices performed outside the home because they contravene rules that are core to the entities of these practices. We seek to supplement arguments by those like Williams (2000) and Charmaz (2010) about impacts of people's efforts to protect their social identity. We acknowledge that anxiety about stigma and identity loss can prompt the omission of type-1 tasks when it is considered unfeasible or undesirable to move to a back-stage location (Goffman 1959). We also argue, however, that people who do insert the use of self-care technologies into everyday life can feel left behind and lose the satisfaction that comes from successfully performing mundane social practices. This study aimed to understand how these material aspects of mobile self-care technologies impact on participation in social practices and whether and how they influence how young people manage chronic health conditions such as type-1 diabetes.

Methods

We explore the ideas just outlined using data from outpatients aged fourteen to eighteen in a paediatric diabetes service in inner London. Approval for the study was granted by a National Health Service Research Ethics Committee and Research and Development Office. Informed consent was obtained from participants and their parents. Names used are pseudonyms.

Recognising that group and one-to-one research contexts can produce complementary perspectives on a question (Silverman 1993), we triangulated our data (see Erzberger and Kelle 2003, Flick 1990, Hammersley 2008) by using both approaches. Focus groups foster greater independence from the researcher, thereby generating greater confidence, spontaneity and openness amongst participants (Levine and Zimmerman 1996); they also reduce the researcher's role in co-constructing meanings, thereby increasing face validity (Lehoux et al. 2006). Furthermore, groups avoid the pitfalls of "outsider oriented discourse" (Bourdieu 1977: 12) and provide greater insight into the tacit assumptions that influence behaviours (King and Horrocks 2010). In contrast, interviews offer greater depth of exploration, facilitate participation from some less confident participants and provide the confidentiality essential for the discussion of some intimate topics (Kay et al. 2009).

We used *maximum variation purposive sampling* to provide a balanced representation of the participant characteristics thought to have the greatest influence on the phenomenon and increase the likelihood that "the full array of multiple realities" would be uncovered (Lincoln and Guba 1985: 40). For the interviews, our sampling process balanced males with females, and children aged 14-15 with those aged 16-18. We also sought to balance those with low, medium and high levels of long-term blood sugar (as measured by *HbA1C*) – though data on this were only available for interview participants. The interview sample was drawn from those attending clinics on those days in July-September when the interviewers were available; the focus group sample was taken from attendees at clinics in the two weeks prior to the December dates set for the two groups to meet. For data protection reasons, participant selection was by a medical professional who already had access to patients' records.

The sample of 25 (10 interviewees; one focus group of 8 participants and another of 7) was distributed evenly between the two age-groups and sexes. *HbA1C* levels were within the recommended range for four interview participants, moderately out of range for five and above the recommended range for one. See Table 1.

Table 1: Characteristics of the participants

			Age		HbA1C when last tested			White British	Other	Total
	Male	Female	14-15	16-18	6.5-8%	8-10%	14%+			
Interviews	5	5	6	4	4	5	1	6	4	10
Focus groups x2	7	8	7	8	----not collected----			8	7	15

The selected patients were sent invitations, information sheets and consent forms. These explained that participation was voluntary, that decisions about participation would have no impact on treatment and that they should respond to a member of their healthcare team or the research team. Each was offered a £15 gift-voucher for participating.

To facilitate access to participants and boost response rates, the hour-long interviews were conducted on the hospital site immediately before or after patients' regular clinic appointments. To allow participants' meanings and narratives to take precedence over the researchers' agendas and reduce the risk of participants telling the interviewers what they thought they wanted to hear (Mahon et al. 1996), the interviews were flexible, 'guided conversations' (Lofland and Lofland 1984). These 'conversations' covered the everyday experience of type-1, impacts on everyday life, practical and emotional responses to the condition, social aspects of living with diabetes and the use of digital resources (which was a secondary interest of the research). Interviewers stressed their role as listeners, set a non-judgemental tone and made it clear they were not medically trained and had no views on medical issues. To avoid any suggestion of a medical model (in what was, after all, a medical setting), interviewers: used 'they' to refer to participants' medical teams (e.g. "Are they telling you to do more blood tests..."); adopted positions of ignorance regarding diabetes care issues; relied on interviewees to explain medical issues; made sure not to voice any assumptions about what comprises 'good' management of diabetes, and encouraged participants to raise whatever topics they considered relevant. As a result, participants were comfortable using discourses not consistent with the medical imperative for concordance/adherence and openly discussed so-called 'non-compliant' behaviours.

Focus-groups were held in the early evening, lasted for about 75 minutes and were moderated by a member of the research team. Parents waited in a different part of the building. In addition to the topics covered in the interviews, the groups included a discussion of what would improve life with diabetes and two ice-breaker activities: a paired activity in which participants asked their partners to tell them three ways in which diabetes had impacted on their lives, and an activity in which groups of three or four were asked to decide whether they agreed or disagreed with a list of assertions describing themes emerging from the interviews (e.g. "I prefer not to tell other people about my diabetes"). Within the loose parameters for discussion set by the topic guide, the young people led much of the discussion and often introduced their own sub-topics. As in the interviews, participants appeared to use the occasion of the group discussions to focus on those occasions when self-care was difficult rather than those when the social context was relatively conducive to the performance of type-1 tasks.

After being transcribed, the interview and focus-group data were analysed in terms of themes that had emerged during the interviews and by using the constant comparative

analysis method (Fram 2013, Glaser and Strauss 1967) to draw conclusions about these data and their context. Given the performative nature of talk about chronic disease (Bury 2001) we examined the use of rhetoric as well as the everyday meanings of statements. At this point, we realised that some of the emerging themes did not fit the frames conventionally applied to adolescents' management of chronic disease and, in line with established practice (e.g. Hargreaves 2011, Watson and Shove 2008), decided to apply a social practice lens to the data.

Findings

Despite the portability of the self-care technologies they were using, participants in this study reported that managing their illness as requested by medical teams caused significant interruptions to their participation in everyday life. As one would expect from the extant literature, anxiety about stigma sometimes prompted participants to interrupt participation by taking illness management tasks back-stage. However, the data also suggest another reason for such interruptions: the demands of the technology and the infringements these demands prompted to the rules of social practices. In fact, the clinical management of type-1 was characterised by some as the antithesis of participation in the social world: as “sit[ting] at home filling in logbooks” rather than “hav[ing] a life” (Charlotte, 14-16 focus-group) or as living “within yourself” (Juna, 16-18 focus group).

In the passages that follow, we illustrate the phenomena that prompted such characterisations of type-1 technologies and encouraged the postponement or omission of self-care tasks. Before doing so, however, we reflect on the evidence in our data for the ongoing importance of stigma. We do this, first, by considering an exchange in the focus group with 16-18 year-olds:

- Haji Only my friends... But like people I don't know, I don't want to like... It's kind of personal to me, the diabetes, because like it's basically my... how my life goes now, my life-style. So I don't share it.
- Abdul If you tell like some people that you have diabetes like, they class it as like a big, big disease like. They make you different. They're like, “you've got diabetes!” Like, they treat you differently as well.
- Brendan Some people... I've actually had... Like, when I was at college I actually had someone who went: “oh, you're diabetic, aren't you.” I went: “yeah”. [He replied:] “Oh, I'm not going to come near you; I might catch it.”
- Juliette Someone said the same about me. Someone said something like... I had diabetic sweets and they're like, “oh, can I get diabetes from these sweets?” and I was like, “you know what, you're not going to have any”. So... And I walk away.

Allusion is made in this exchange to each of the accepted characteristics of enacted stigma (Link and Phelan 2001): disconnection (“I'm not going to come near you”; “I walk away”); loss of status (“making you different”), and discrimination (“treat you differently”). This enacted stigma leads to felt stigma – as also seen when Harid (17, interview) explains her embarrassment when she imagines people asking themselves “what is she [doing]?” It also impacts on the young people's willingness to engage in

front-stage self-care – e.g. when Fahad (15, interview) reports that the “shame” associated with injecting in front of others “makes you feel like you just don’t want to do it”.

However, although there is some allusion to stigma, the data suggest that improved portability may have somewhat normalised the use of type-1 technologies and reduced the sense of embarrassment and stigma associated with the performance of self-care tasks in front of intimate, trusted acquaintances. Like other participants, Haji (16-18 focus group) makes a clear distinction between revealing self-care tasks to his friends and to performing them in the sight of “people I don’t know”.

Although issues with stigma might have been ameliorated by the portability of modern technologies, the data suggest that this portability has brought additional interruptions to users’ participation in social practices. Our first example of this is the interruption of one young man’s participation in the practice of going-to-the-park:

One time I was [going to] Hyde Park and [we] were all going to go in and just at Marble Arch station I was like, “let me nip to McDonald’s so I can just do a quick blood test”. And they were like, “oh, we’ll meet you in the park then”. And so it, kind of, like... it kind of just leaves you behind.
(Zeb, 14-16 focus group)

As this shows, neither time nor space was allocated to type-1 care within the practice rules of going-to-the-park. There is no suggestion that Zeb’s friends stigmatised him for his actions. The issue, rather, is about the rules of the practice, which appear not to permit interruptions for personal care. Although it takes less than five minutes to do a blood-test back-stage, Zeb explains that “people just don’t want to wait”; they “just want to [...] carry on doing what they’re doing” and so “sometimes you get left behind a bit”. As a result, Zeb is excluded by his friends, albeit temporarily, from the performance of this practice.

Similar sentiments are implied in the interview with Eric (15, interviewee):

If, like, [my friends] were running around and stuff, and they just say, “Oh come on Eric, come on, hurry up”, and I’d be doing my injection, it’d be like, “well I can’t because I’m...” If I could just run off and stuff... I would if I could, but I can’t.

Again, there is no indication here of stigma. Indeed, Eric indicates elsewhere in the interview that he is happy for friends to witness his type-1 activities: “I’ve known a lot of people that do it privately. [...] But I don’t mind. Like my mates are asking questions about it, and I answer them.” However, the text does imply that the rules for running-around are broken by Eric when he takes time out. Hence, Eric’s interrupts his participation in the practice.

Another of Zeb’s stories (16-18 focus group) illustrates a similar phenomenon – this time within family practices.

If you’re going out for a big meal with your parents, somewhere special like, your parents are always like, “oh, go and do a blood sugar”. But you’re so excited to have your meal, you just don’t want to. But, they’re, like, “oh go do it”, so you have to run and then they’ve all set into their food by the time you get back [laughs] – it’s like, “thanks!”

Zeb makes it clear that the rule for the social practice of family meals-out is that blood tests must be conducted away from the table. Furthermore, there appears to be no rule about waiting for a person to conduct their self-care tasks before the meal begins – by the time Zeb returns, “they’ve all set into their food”. The result is that Zeb misses out on the start of a symbolic, much-anticipated “big meal”. As suggested by Zeb’s ironic “thanks!” he feels himself to have been left behind.

While in the above examples self-care tasks were allowed to interrupt participation in friendship or family practices, there were also examples of self-care tasks being postponed or omitted in order to avoid such interruptions. Methanwe (14-16 focus group) reports that she “can’t really be bothered to do injections or [count carbohydrates]” when she is out with friends. Mangit (14-16 focus group) says she prefers not “to think that I have diabetes when I’m with my friends, even though they all know” and that she therefore “rather do[es her injection] later”. Fahad (15, interviewee) argues that although his friends know about his type-1, it is “a lot easier” to delay his injection until after a meal rather than doing it at the table with them. As tacitly suggested by “can’t be bothered”, “rather do later” and “a lot easier” it was the desire to avoid interruptions to participation in social practices that motivated interruptions to the management of type-1.

Other participants are more explicit about their desire to prevent type-1 from interrupting their social activities. Jocasta (14, interview) says she prefers using an infusion pump to doing injections because the pump allows her to take insulin with little interruption to what she is doing; this, despite the pump arousing a “kind of annoying” curiosity in others because of its visibility. Her interview suggests an integration of the disease with her social identity (see Williams 2000) and the absence of any sense of stigmatisation: she describes liking the “sympathy” she receives from her friends and that it is “nice talking about [type-1]” to new acquaintances. This absence of stigma makes her reluctance to interrupt “relaxing with friends” practices all the more pertinent to our discussion. In a similar vein, Selina (14-16 focus group) reports leaving injections until “later” if she would otherwise be “holding [her friends] behind”. Again, there is no indication of anxiety about stigma. It is clear in these two examples that a conscious attempt is being made to balance self-care and social participation. Good management of type-1 is important for both. Jocasta is a “control freak” about her condition because “it will have an effect on me if I keep having high numbers” and Selina, “know[s] diabetes should be [the] priority”. Despite this, an aversion to interrupted participation in social practices leads them to sacrifice self-care when the rules of the social practice do not allow for it.

Our penultimate example of social practice obligations deterring self-care illustrates how this can co-occur with stigma avoidance. This is illustrated when Brendan (16-18 focus group) describes a football refereeing experience:

I'm told to take blood tests at half-time but if you've got two touch judges with you as well, you haven't got time. When you're talking to them about, like, the first half, you haven't actually got time to check your blood test.

Brendan has at least three options regarding the half-time blood test requested by his medical team: do it while talking to the touch judges, retire to a back-stage location to do it or omit it altogether. His account suggests two reasons for his choosing the third option. One of the possible reasons, stigma avoidance, is suggested by his comment,

elsewhere in the discussion, that he sometimes feels “like a bit of a freak” when strangers notice him doing type-1 tasks in public. Alongside this, however, Brendan’s emphasis on “time” indicates that a second reason for omitting the blood test is that he does not want to interrupt the half-time social practice for match officials: either by doing the test in front of the touch judges, which might distract him and them from the conventional topics of conversation, or by going to a back-stage location and either foreshortening or preventing that conversation.

Our last example of the clash between social practices and the use of mobile self-care technologies is located within the routines and material structures of the school lunch-time:

...it’s like I’m rushing all the time, so I don’t really do the carb-counting [as] correctly as I can; so I just quickly do everything. [...] I go to the queue, get my food, eat it, go toilet and then I just write what I ate, take my blood glucose, count it up. If I need to do corrections, I’ll do it. And I have to wait for the queue, people getting out the toilet, and then I inject myself, and by that time the school bell has already gone and I get five or ten minutes late to the class and the teachers think I’m always using my diabetes as an excuse. [...] So sometimes I don’t even take my injections, because some teachers are very strict [...]

(Harid, 17, interview)

Here, the formal nature of some of the practice rules make the phenomena we identify stand out more clearly than in the earlier examples. As indicated in Harid’s account, the coordination of lunchtime practices with the densely populated timespaces of the school-break make it difficult to perform the necessary tests, calculations and injections without falling foul of the practice rules of the school day. Harid’s decision to take these tasks back-stage (in order, presumably, to avoid the risk of stigma) exacerbates the disruption, but her comments suggest that practice rules also play their part. Carbohydrate counting, blood tests, dosage calculations and the injection itself require time, cause Harid to miss out on informal lunchtime practices and leave her vulnerable to sanction for breaking formal practice rules.

Having provided numerous examples of how the integration of type-1 tasks with social practices causes difficulties, we move on to an illustration of how the problem of practice interruptions falls away when self-care tasks are integrated into, and congruent with, other social practices. This illustration comes from Becky’s (14, interviewee) tale of a weekend conference for people with type-1:

Becky: [...] you were always reminded to do your needles and when we had lunch and stuff there was all, like... we were all separated from, like, carby foods. Oh it was really fun. [...]

Int: What was good about that event?

Becky: It was just really cool to see all the different people with diabetes. Like some people were really good at it and some people were like me, and we all did our blood sugar at the same time once and they were like literally all exactly the same kind of reading. It was really cool!

This passage depicts a situation in which type-1 tasks, rather than being one-off variations in practice performances, are integral parts of practice entities. Becky is able to include type-1 tasks in her practice performances without risking stigma,

experiencing scheduling problems or interrupting other social practices. Earlier in her interview she, like other participants, suggested that reluctance to interrupt other practices sometimes prompts her to neglect self-management tasks. In this passage, in contrast, self-care activities are described as “fun” and “cool”. The significance of this to Becky is indicated by the animation and engagement unique to this part of the interview, and by her use of exaggeration (“*literally all* exactly the same kind of reading” – emphasis added) to indicate the symbolic importance of this being a shared, briefly normalised, act. A collective agreement on the interweaving of timespaces allows diabetes to be performed front-stage without disrupting the coordination of shared practices or risking a spoiled identity.

Discussion

This paper highlights an aspect of life with a chronic disease hitherto paid little attention in the literature: the challenge of accommodating the demands of self-care technologies into the densely organised timespaces inhabited by social practices, and to do so without infringing the rules of these practices. The conflict between the needs of self-care and the rules and timespace demands of teenage practices demonstrates how the agency of people with chronic disease is bounded not only by “social and bodily resources” (Brady et al. 2015) but also by practice rules that constrain when they can use those skills and resources. As this analysis confirms, the technical skills needed for self-care are, by themselves, insufficient for holistic disease management (Bury 2010, Charmaz 2010). By using a social practice approach, we have demonstrated how, if they are to exert true agency, people with chronic disease need to establish a *modus vivendi* that balances the concerns of the social order (practice rules) against the more visceral demands of disease management technologies.

Unlike some previous commentators (e.g. Kelleher 1988, O’Connor et al. 1997) our research suggests that it may be outwith the capabilities of adolescents with type-1 to preserve to social order whilst also preserving their physical health. This is because type-1 tasks are not integrated within other adolescent social practices, and so compete with these practices for a share of the timespace. If performing these tasks involves suspending other practices and getting ‘left behind’, the perceived social cost is so high that young people can feel there to be no viable option other than the neglect of disease management.

This paper suggests that social constraints on disease management operate at the meso level, not just at the macro level indicated by Scambler (2006). The formal rules of refereeing would have permitted Brendan to go back-stage for a half-time blood-test, and he was bodily able to do so. However, informal practice rules obliged him to chat to the linesmen and prevented him from testing his blood while doing so. Hence, while commentators have elsewhere argued that the disabling effects of chronic disease should be countered by political action at the macro level – for example, against the hegemony of individualism, competitiveness, self-responsibility and healthism (Monaghan and Gabe 2018) – our use of practice theory emphasises the importance of addressing meso-level social forces.

Our analysis suggests that these meso-level forces would be reduced if disease management tasks were embedded in relevant everyday practices and integrated within practice rules. Becky’s description of her conference weekend illustrates this by

depicting a situation in which type-1 tasks were an integrated part of eating practices. It might not be viable to replicate the situation at the conference in society as a whole. However, it is possible to imagine other changes to the social rules of eating practices – for example, the (re)introduction of a timespace for people to engage in illness management prior to eating (as well as to conduct cleansing rituals such as hand-washing). Similar rule changes can be imagined in the world of organised sport, where the management of physical health is part of many practices (Balfe 2007) and where timespace concessions have already been made to health-related behaviours such as stretching, nutrition and hydration (e.g. warm-up areas and pit-stops). One could imagine these concessions being extended to include the management of chronic illnesses. Examples might include changes to the temporal and material resources available during half-times, end-changes and other breaks, or developing equivalents to the rugby 'blood replacement' for those needing to tend to chronic health conditions.

Formal sport and mealtimes are special cases, however, and to reflect more broadly on the insertion of self-care into other social practices, we need to consider the nature of social practices. The contemporary emphasis on health and fitness as prerequisites for sporting excellence renders sport particularly amenable to the inclusion of health-focussed behaviours; so too, the contemporary association of health and diet, which can facilitate the insertion of self-care behaviours into mealtimes. As a result, when self-care asserts a presence onto sporting events and mealtimes, it does so as what Schatzki calls a *dispersed* practice. Schatzki (2010) contrasts *dispersed* practices with *integrative* practices. The former consist of complex sets of actions organised according to specific purposes and beliefs (Schatzki 2010) – examples in this paper include the practices of running-around, family-meals-out and going-to-the-park. Dispersed practices, in contrast, centre around single types of action (Schatzki 2010), adhere to the aims of other practices and become integral to the successful performance of these other, integrative, practices. One example of a dispersed practice is walking (Harries et al. 2016). Although walking can sometimes itself be the purpose of a practice (e.g. in hiking), it is more commonly the servant of other purposes – such as when it facilitates the traversing of supermarket isles so that food can be collected and purchased. Formal sport illustrates the inclusion of dispersed health practices – and sometimes chronic illness practices (Balfe 2007) – within integrative practices. Dispersed health practices are also evident in some mealtime practices: for example, when restaurants provide the calorie content of their menus and/or brand some meals as particularly healthy. In these examples from sport and catering, health practices no longer need to compete for time and space because they are constitutive parts of integrative practices that are already being performed.

More commonly, however, health is not one of the aims of social practice entities, and self-care practices are unable to disperse amongst them. In such circumstances, the management of chronic illness remains an integrative practice and is obliged to compete for time and space with other integrative practices to which people are expected to give a higher priority (Southerton 2006). The frequently dense temporal interweaving of these other integrative practices makes it difficult for integrative health practices to gain time and attention without causing their performers to become dislocated from the social life around them. In such cases, people are obliged to choose between a disabling loss of social integration or inattention to the management of their disease. Just as the physical infrastructure of society can disable people with limited mobility (Oliver 1990, Thomas 2012), so the temporal-spatial organisation of social practices disables those whose health conditions demand the ongoing use of

self-care technologies. By allocating individual care tasks a contingent location in social schedules, society obliges those with type-1 to choose between social integration and optimal biomedical management of their condition.

It is possible that the inclusion of dispersed self-care practices within other, integrative social practices, would be facilitated by designing disease management technologies to be less stigmatising and to fit better into the timespace dimensions of young people's social practices. However, this would only represent one step towards the integration of disease management tasks into the practice entities of school lunch-times, family meals out, football matches etc. Our work indicates the need for further exploration of the other factors that would facilitate such integration, and of the links between chronic disease and the performance of social practices.

This paper shows the benefits of using practice theory to study the self-management of chronic illness. Use of this theory prompted us to reflect on the position of self-care practices within the network of practices that constitute social life, and to consider the implications of how these practices compete for time and space. In addition, by mapping the main elements that influence self-care behaviour and obliging analysts to straddle the agency-structure divide, social practice theory opens analysts' eyes to a wider range of potential influences on self-care behaviours. In this study, our data led us to focus on three of the elements of social practices: rules, aims and materials. The materials and processes associated with blood tests, injections and carbohydrate-counting demand time, mental concentration and – if stigma is to be avoided – physical relocation. Our study has shown how conflicts with the rules and aims of everyday integrative social practices can deter use of technologies for the management of chronic illness. These phenomena have received insufficient attention in the past – in part, we suggest, because of the lack of an overarching framework such as that provide by social practice theory.

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