
‘Everybody has to think – do I have any peanuts and nuts in my lunch?’ School nurses, collective adherence, and children’s food allergies

Vanessa Lopes Muñoz

Department of Sociology, Colorado College, USA

Abstract Developing robust explanations for patients’ non-adherence to medical treatments is a pressing clinical concern. Social scientists have emphasised the importance of taking a ‘patient-centred’ approach to the study of illness management. Using data from a qualitative study of the management of children’s food allergies, I found that school nurses created what I term collective adherence – the translation of individual medical recommendations into prescriptions to be followed by entire communities. School nurses secured collective adherence by aligning physicians, schools, and families around a particular interpretation of medical recommendations, setting guidelines of behaviour for the entire school community to follow, and balancing the diverging needs of illness sufferers and non-illness sufferers. This study contributes to the study of adherence by examining the medical recommendation as a dynamic prescription, extending adherence to the study of ancillary providers’ interaction with medical recommendations, and examining the impact of illness on non-family ties. I conclude with a discussion of implications for the field of school nursing; and potential applications of the collective adherence framework to the management of health conditions and health risks.

Keywords: compliance/adherence, children, parenting/parents, nurses/nursing, illness behaviour

Researchers estimate that patients modify or otherwise do not follow doctors’ recommended treatment plans about 50 per cent and as often as 80 per cent of the time (Greene 2004, Segal 2007, World Health Organization 2003). This practice, patient non-adherence, is one of the most pressing concerns in clinical research. Sociological studies in the patient-centred tradition point to the critical role of illness sufferers’ daily lives in shaping how patients manage their health conditions (Adams *et al.* 1997, Bissell *et al.* 2004, Conrad 1985, Murdoch *et al.* 2013). As chronic illness becomes increasingly about managing risk, rather than managing symptoms (Aronowitz 2015), the multitude of actors and settings involved in managing health will likely become more relevant to studies of adherence. Currently the adherence framework has some shortfalls in this regard. Medical recommendations themselves remain largely unexamined despite signs that they are ambiguous and dynamic (Greene 2004, Hayes-Bautista 1976, Mishler 2008). Also, there has been limited attention to non-medical settings and the multiple actors involved in managing health, including those who share institutions with ill persons and ancillary medical personnel.

Using the case of the management of children's severe food allergies in US elementary schools, this paper is an examination of how medical recommendations are implemented within communities and by multiple actors surrounding those with a medical condition, a process that can impact the course of adherence. Using interviews and observations, I examine the process of securing 'collective adherence' – the conversion of treatment plans to school-wide policies with the collaboration of various public caregivers and school community members.

Adherence

The physician-centred approach to the study of adherence has its inception in the work of Talcott Parsons (1951), who conceptualised physicians as gatekeepers, temporarily excusing sick people from their responsibilities if they agreed to see a doctor, followed the doctor's recommendations, and worked to recover. Scholars have since found considerable variability in the degree to which patients follow physicians' recommendations, yet there are very few explanations for these complex patterns of patient non-adherence (Greene 2004, Starr 1982). While there is some evidence that physicians' behaviour, such as clear communication, contributes to patients' following recommendations, there is also evidence that decisions about adherence extend beyond patients' comprehension of recommendations (Donovan and Blake 1992, Hall *et al.* 2009, Heritage and Maynard 2006). Some scholars have explained non-adherence as part of an overall decline in physicians' authority, resulting from shifts in the role of pharmaceutical companies, health insurance plans (Light 1991, Mechanic and Meyer 2000), and patient groups (Barker 2008, Conrad and Leiter 2004). Despite overall declines in adherence rates, most studies found that physicians continued to dominate interactions in the clinic (Pilnick and Dingwall 2011). This pattern is one that some researchers and policy makers believed would be remedied if physicians and patients collaborated to create treatment plans – a model referred to as 'concordance'.¹

Patient-centred studies, on the other hand, have asserted that social factors outside of the clinical encounter shape patients' decisions (Adams *et al.* 1997, Conrad 1985, Donovan and Blake 1992, McCoy 2009). Patients and physicians often articulated different priorities when lay needs were distinct from professional goals (Burton and Hudson 2001, Hayes-Bautista 1976, Mishler 2008, Morgan and Thomas 2009, Prout *et al.* 1999, Venn and Arber 2012). Socioeconomic resources and status could also create barriers or enable patients to follow medical regimens (Lutfey and Freese 2005, Shim 2010). Social relationships sometimes factored into health decisions, causing patients to structure medication-taking around their social commitments (Conrad 1985, Gregory 2005). Finally, people's preferences to minimise the number of medicines that they took could result in modifications to physician recommended medication regimens (Pound *et al.* 2005, White *et al.* 2013).

Food allergies

In the United States, it is estimated that four to eight per cent of Americans suffer from one or more food allergies, potentially life-threatening immunological responses to food proteins (Braun and Lukacs 2010, Gupta *et al.* 2011). The most severe reaction is anaphylaxis, which can result in a closing of the throat and/or a severe drop in blood pressure (Atkins and Bock 2009). Anaphylaxis is typically treated with an intra-muscular injection of epinephrine (i.e. 'Epipen' is a brand commonly used in the US).

Food allergies are a useful case for a patient-centred study of adherence outside of a medical setting because of the significant involvement of non-medical institutions, such as schools and day cares, to children's food allergies (Branum and Lukacs 2010, Christakis 2008, Waggoner 2013). The social response to the threat of food allergic reactions is very visible in national and state guidelines for the management of food allergies in schools (Centers for Disease Control 2013). School policies range from removing the most common and severe food allergens, often peanuts and tree nuts, from schools to banning them in classrooms where children have nut allergies. School nurses are at the forefront of managing chronic conditions and emergency preparedness in schools; and are present in about 79 per cent of US public schools (Bonaiuto 2007, Borup and Holstein 2010, Department of Education 2012, Guttu *et al.* 2004, McCarthy *et al.* 2000, Olympia *et al.* 2005, Taras *et al.* 2004).

Although school nursing began as a public health profession in the early twentieth century, their work has since shifted to individual health promotion, with medication administration being the most common health-related activity that school nurses perform (Brown and Piper 1997, Hawkins *et al.* 1994, Leo and Clark 2007, McCarthy *et al.* 2000). Despite this apparent shift to health promotion, scholars still identified a tension between the public health and individualised health focus of school nurses (Lightfoot and Bines 2000, Merrell *et al.* 2007). Some scholars found that there was considerable role ambiguity as school nurses served the aims of nursing and those of school administrators (Reutersward and Lagerstrom 2010).² School nurses' location between public health initiatives and school administrations places them in a unique position to manage the individualised and public health dimensions of food allergies.

Adherence decisions in schools also involve families, who are a major actor in managing children's food allergies and other chronic conditions. For families, protecting children from accidental exposure to food allergens – everyday foods – also poses various challenges, including reduced quality of life and increased psychosocial stress (Bollinger *et al.* 2006, Flokstra-de Blok *et al.* 2010). In a study of parents of children with food allergies, Stjerna *et al.* (2014) found that parents managed the risks associated with food allergies through constant vigilance, which they characterised as fundamentally a 'social project' mediated through interaction and communication with others. Scholars have also been attentive to the metaphoric value of allergies as health conditions emblematic of the twentieth and twenty-first centuries (Jackson 2006, Mitman 2003). Nettleton and colleagues (2009: 648) have called for sociologists to be attentive to the potency of the case of food allergies, arguing that there are 'parallels between debates on food allergies and other contemporary socio-political concerns'.

Methods

The study

This paper draws mostly from interviews with school nurses (N = 18) in 12 different elementary schools. These interviews were collected as part of a larger study conducted from 2011 to 2013 that included interviews with paediatric allergists, parents of elementary-aged children with food allergies, children with food allergies, school nurses, and relevant school personnel. The larger study also included participant observation in an allergy clinic, allergy related events, and two elementary schools. Institutional Review Board approval was obtained from a university, one public school district, and a public hospital.

To conduct the interviews, I began with interview guides that detailed open-ended interview questions. I subsequently adapted questions to the nuances of each personal narrative and added questions based on participant observations (Weiss 1995). Interviews with school nurses were informed by observations in schools and at allergy-related events and interviews with

parents and physicians. In school nurse interviews, they were asked to describe a typical day, their management of food allergies, and their interaction with parents and school members. Parents were asked to describe when they first learned about their child's food allergy, their previous allergic reactions, their clinical visits, their daily management of food allergies, and their experiences with their child's school. Interviews lasted between 50 and 120 minutes. Interviews were audio recorded and transcribed verbatim. I edited quotes used in the paper for the purpose of clarity, removing verbal pauses, repetition, and false-starts that did not indicate hesitation or uncertainty.

Participants and recruitment

The school nurses interviewed in the study worked at schools located within one hour of a metropolitan area in the north east region of the United States. To classify schools as serving working-class and middle-class families, I used the percentage of students eligible for free and reduced lunch, a common proxy for US children living in low-income households, and median home income values in the school district. The schools' student bodies were comprised of children from a range of racial/ethnic backgrounds and schools were located in urban and suburban settings. At each site, I interviewed the school nurse, obtained a tour of the school, and when relevant, was given written documentation of the school's allergy policy. I used a convenience sample and contacted local school nurses directly by email or phone to request an interview. When I explained the study to elementary school nurses I told them that I was studying the management of food allergies in schools and how they participated in this process.

Two elementary schools became focal research sites where I also recruited and interviewed parents of children with food allergies and conducted selective observations during lunchtime in the school cafeteria. East Side Elementary was a school that served primarily working-class Latino families; parents had limited education, such as a high school degree or a college degree from another country that did not hold an equivalent value in the US; and they worked in service or low-wage occupations if they worked outside the home. Middlebury Elementary served primarily middle-class White families; parents had a college degree and often a graduate degree and held managerial jobs if they worked outside the home.

Analysis

I conducted the first round of preliminary analyses by reading interview transcripts using Atlas.ti qualitative data analysis software (Timmermans and Tavory 2007). I used this initial round to look for preliminary themes that I then used to modify interview guides. Initial themes that arose in transcripts were about coordination, complexity of food allergies, garnering and making sense of diagnoses and physicians' recommendations, liability, and managing parental expectations. The research question that emerged was how do parents and school officials make decisions about adherence to food allergy management regimens in the school setting? I then looked for confirming and disconfirming evidence in remaining interviews and observations and crosschecked for validity (Miles and Huberman 1984). Upon reviewing the literatures on illness experience, compliance, adherence and concordance, I began developing these themes into the collective adherence framework outlined in this paper.

Findings

Collective adherence

A precursor to adherence in schools was determining the treatment plan and finalising the appropriate medical recommendation to be followed. At times this process involved clarifying

the medical recommendation. To clarify the treatment plan school nurses aligned physicians, families, and school community members. School nurses then worked to secure 'collective adherence' – by recruiting various caretakers and non-ill school members to enforce this treatment plan and by balancing the interests of ill and non-ill members of the school.

The collective adherence framework is founded on the assumption that decisions about following medical recommendations are embedded in people's daily lives – a central sociological contribution to adherence studies (Conrad 1985, Lutfey and Freese 2005). The collective adherence framework also draws from the concordance model in that collective adherence shifts the emphasis from patients and singular medical providers to the interaction between patients and medical providers in developing treatment plans. Finally, collective adherence also attends to the role of non-illness sufferers and non-medical caretakers in the process – namely children without food allergies and their families, teachers and school administrators.

Clarifying the recommendation

Nurses spoke about medical recommendations as dynamic directives that were clarified into treatment plans through negotiation. The primary actors involved in determining the ultimate course of food allergy management were physicians, the school community, and families of food allergic children, which included the children themselves. School nurses worked continuously to align all three groups to negotiate a treatment plan for everyone to follow during the school day.

Nurses reported obtaining health forms from parents that outlined the child's food allergies, related health conditions, and treatment plans. The health forms were a written record of the recommendation of physicians and the input of parents. Once parents arrived at schools with medical recommendations for their child's care, school nurses worked to clarify these recommendations by aligning physicians, parents, and the school.

Some nurses said they would follow the physician's orders closely. One school nurse, Joan, from a primarily working-class school, was interviewed after she attended an information session that was led by a food allergy advocacy organisation and featured Dr. Clark, an allergist that advised against giving an antihistamine. Joan said:

If it's one or two rashes, we have Benadryl orders for all of them. The Benadryl order comes with it, most of them. Whereas Dr. Clark's changing that. Dr. Clark said to his clients, he's not putting the Benadryl. So if I got one of his orders, if it says, 'Give epinephrine', I would totally do that.

This example highlights the variation in physician's orders for food allergy treatment. Nurses reported that different physicians wrote different orders based on variations in children's health status (for example, whether they had asthma, which could increase the risk of a serious allergic reaction). Even for children with similar health profiles, physicians did not all recommend the same treatment and response to allergic reactions (see Gupta *et al.* 2014). This created a variety of treatment recommendations, even among children with the same health condition, for food allergies.

The decision about how to treat an allergic reaction was also shaped by nurses' assessments of children, especially in cases of severe allergic reactions. As one nurse explained, 'If a child comes in with that kind of a reaction, I don't pull the order. I look to see what I have in front of me'. The nurses interviewed reported that their assessment of the child was a key determinant of what treatment they would administer, at times irrespective of the physician's order. Another nurse explained her assessment process, in which she contacted the physician in reactions she believed were mild.

Many emergency plans say go straight to the Epi-Pen. . . typically what I'll do if I'm not sure, I'll do a whole allergy check, their eyes, their nose, their mouth, listen to their lungs, look at their bodies, itchiness, really get a picture and if I really feel that this really looks mild in a way that I'm not feeling we need to go to Epipen, I'll call the doctor and I'll say, 'I'm running this by you. This is what I'm thinking. What do you think?' and I've never been told when I made a call like that, 'Go to the Epipen'.

The physician's initial recommendation, as written on the medical form, was clarified through the nurse's assessment of the child's physical condition during the allergic reaction. The nurse's expertise, the school's liability, and the physician's input all factored into her decision not to administer epinephrine. The medical directive was ultimately dynamic and subject to interpretation by the nurse.

Aligning families, schools, and doctors

School nurses, in order to clarify recommendations, also worked to align families, physicians, and schools. The alignment of the expectations of physicians, families, and school communities was most explicit and complicated in cases where there was disagreement about food allergy management. One example is Nurse Emily from East Side Elementary and kindergarten Maria who had a tree nut and soy allergy. Nurse Emily described Maria's parents as 'soo soo nervous at the beginning of the year, petrified to let her come [to school]'. The parents came to school with 'a note from the doctor and a big long note that they had [hand] written [to] me'. Despite Maria's persistent begging and crying that she wanted to eat chicken nuggets at lunchtime, school personnel made accommodations to provide safe foods for Maria during school lunch, such as saving leftover soy-free snacks and juices from school lunches to be used on days when the school lunch contained soy.

Over time Nurse Emily noticed that Maria's parents sent her with snacks, which Emily discovered were 'all soy stuff, but she eats it and she's fine. It's a nightmare'. In an effort to reconcile Maria's allergy and the soy-containing snacks that Maria brought to school, Nurse Emily contacted Maria's doctor. She recounted:

I actually called her allergist and she said, 'well generally the soy allergy is not an anaphylactic life threatening allergy, it's more like a GI [gastrointestinal] distress type thing'. She's like 'so it's probably fine'.

The doctor's verbal statement that Maria is not likely in danger if she eats soy is not aligned with the doctor's initial recommendation of strict avoidance, resulting in an ambiguous recommendation.

Even though Maria's parents were sending her to school with foods containing soy and Maria wanted to eat those foods – a form of patient non-adherence to the written recommendation – Nurse Emily continued to restrict Maria's diet at school in an effort to enforce adherence during the school day. Emily concluded:

She's a struggle every day because she'll be crying because she'll want the nuggets and then they [the lunch assistants] will bring her to me and I'll be like 'Maria I'm sorry, I can't let you eat them'. It's a mess.

By following the written recommendation, the school impacted the course of the child's adherence to the initial doctor's recommendations. The school health form, which states that Maria cannot eat soy, is another mechanism for the enforcement of adherence.

The schools' interests, such as concerns about liability or resource constraints, did not always outweigh families' input when it came to determining the final treatment plan. Nurse Laura from the affluent Middletown Elementary School recounted a story about the parents of a kindergartener, Jamie, with a peanut allergy. Jamie's parents, who were very anxious at the onset of kindergarten, arrived at the school with a clear demand: they 'wanted every touching object sanitised' before their daughter entered the classroom in the fall. While it was fairly common for teachers to wipe down tables where children ate, hundreds of non-food related classroom items were not typically cleaned to avoid food contamination. To meet the requests of Jamie's parents, Nurse Laura spent 'twelve hours cleaning the manipulatives' over the summer. She explained:

I didn't have enough medical data at that point to say to the principal 'we shouldn't do it', and the doctor felt like 'do what you can do' and wouldn't say to the parent that's not reasonable.

Once the physician and the parent were united in their request, which was aimed at reducing risk to the child, it was difficult for the school nurse to deny the request even though it created a heavy burden for school staff.

While she did not convince the child's paediatrician to contradict the parents' requests, Nurse Laura did eventually leverage the perspective of the school – that sanitising these classroom objects was typically burdensome and medically unnecessary – to reject similar future requests. She explained:

I would pull my notes from those [nurse continuing education] conferences and say this is what I've been taught and this is the evidence, and I would also give them my own experience in our cafeteria.

In this case, medical research (buttressed by previous experience) served to counterbalance the family's individual physician's recommendations and parents' preferences.

This alignment of the perspectives of medical providers, school members, and families, while it could shift as in the example above, tended to favour perspectives that were viewed as being most likely to reduce risk. Schools tended to act in favour of parents who pressured them to engage in behaviours that were more risk-averse than the default school policies. In instances where parents advocated for riskier behaviour, they were often less effective in shaping schools' actions. Thus, when children were in the care of schools, the ability of families to not adhere – what Stjerna *et al.* (2014) refers to as 'situated risk-taking' – was more limited.

An example of parents requesting that the school pursue a riskier treatment is exemplified in a story that circulated among school nurses in a middle-class school district. The school district nurse supervisor, Gail, recounted how she and a high school nurse handled a peanut-allergic high schooler who ingested a cookie believed to contain peanuts.

We called the parents . . . We always call the parents to let them know we've call[ed] 911 and have them meet the child at the hospital. The parents said, 'don't give it [epinephrine injection]'. We called her doctor. He said, 'give it'. It was 'drama'. Parents showed up. It was financial. They didn't want to pay for the Epipen [epinephrine injection] and didn't want her to go to the hospital either. (field notes)

The parents' concerns, that they did not want to have to purchase a replacement 'Epipen' and pay for a hospital visit, did not outweigh the medical concerns of the doctor. The family

expressed being burdened by the costs of picking up their child at the hospital and paying for associated fees.³ Lutfey and Freese (2005) have shown how the social costs of following through on doctor recommended treatments, for example employment constraints, could lead to non-adherence. In the school setting, rather than resulting in non-adherence, the burdens that families faced would be weighed against potential risks to the child and liability for the school.

School nurse interviews from Middlebury Elementary and East Side Elementary, the two focal schools of the study, showed that middle and working-class parents varied in their degree of input into school food allergy policies. There is also some evidence that school nurses themselves contacted middle-class parents more frequently to seek their input on decisions related to managing children's food allergies. At the middle-class serving Middlebury Elementary, Jamie's parents reportedly pressured their doctor and made very specific demands on the school. In interviews with other nurses serving middle-class families, school nurses reported parent-driven allergy action plans and policies, such as a school that 'went nut-free' because the parents of one child pushed very hard to eliminate nuts from the school. A school nurse in an affluent suburb said 'the administration 'felt if they didn't [go nut-free], they could be held liable'. This is analogous to the parental pressure reported in studies of educator-parent interactions (Lareau 1989/2000, Lareau and Muñoz 2012, McGrath and Kuriloff 1999).

In contrast, at the schools serving working-class students, nurses rarely gave examples of parents exerting pressure and when they did, the schools did not ultimately change policies in their favour. While Maria's parents went to the East Side Elementary school nurse to express concern about their child's food allergy, they did not make any specific requests for her food allergy management and they were almost completely outside of the process when the school nurse worked to establish what treatment plan the school should follow in managing Maria's soy allergy. While studies do not indicate differences in perceptions of risk based on social class, variation in the quantity of requests made by parents of different social class backgrounds may explain the greater influence of middle-class parents (Beck 2006, Lareau 2003/2011, Lareau and Muñoz 2012, Villalobos 2014). Furthermore, nurses in schools serving working-class children appeared more hesitant to contact parents; the degree of nurse-parent communication may also have contributed to the greater influence of middle-class parents. For example, when Nurse Emily from East Side Elementary was concerned about Maria's soy-containing snacks, she did not contact Maria's parents. Whether this was due to concerns about their availability or their limited language ability, this action further reduced their potential to influence the final decision about what Maria could eat at school.

Securing the adherence of many

School nurses, once they had negotiated the terms of the treatment plan among school members, families, and doctors, had to recruit multiple actors at the school to comply with the school's allergy policies. Securing compliance involved persuading different actors to monitor their behaviour and that of others in order to protect children with food allergies. There was considerable preparation and recordkeeping involved in creating a system for this monitoring to occur. Most cafeterias were equipped with lists of the names and pictures of children with food allergies on large poster boards, binders, and/or computer screens.

Parents and children with food allergies were often the first target of school nurses' policies. Initial interactions, when parents informed school nurses of their child's food allergy, were similar to traditional patient experiences in that the child was the patient and the parent was a proxy patient expected to carry through with the recommendations (Timmermans and Buchbinder 2012). One nurse explained her position vis a vis the parent and child in the following way:

my colleagues to them I say 'you should carry your work Epipen', but I cannot make them do it. Versus a student [to] who[se parents] I can say, 'I'm sorry, if this is a life-threatening situation for you then your child must have Epipen available to me'.

When asked what she would like to see changed in the future, another nurse said:

Parents update us! Like if the kid went to grandma's house or went to a Chinese restaurant over the weekend or over the holidays – I would hope the parents would let us know that the kid had a reaction. I would. I want to know every time the kid has a reaction.

Parents had the responsibility for managing their child's allergy and keeping the school nurse informed about their child's health condition.

Children with food allergies were expected to closely monitor themselves as well. One nurse said:

I don't take it from just the parent. I immediately call the student down. It's like, 'Hi! Mom said that you have a reaction to peanuts'. No, I ask the student what they have an allergy to, and I let the student tell me. And then I go further with the teaching. Of course, its age appropriate, on labels, eating, not eating other kids' food.

Various nurses spoke about educating the food allergic child with the goal that, as one nurse explained:

by fifth grade we're hoping they are looking at labels themselves or if somebody's offering them something they're questioning what's in it. Or if there's no label or ingredients to look at, they don't just say, 'Sure, I'll have a bite'.

'Teachers are like peanut butter sniffing dogs'

After parents and children, school nurses turned to teachers and other school staff members to take part in managing food allergies because as one nurse explained, 'parents are relying on the adults to watch them [their children] to make sure the foods that are given to them from school are okay for them to eat'. Teachers and staff were trained to protect children from potential exposures to allergens. Using tools that the school nurse prepared, school personnel learned the specific allergy needs of individual children. Nurse Sharon spoke confidently about the preparedness of the cafeteria staff in managing allergens that children may accidentally ingest:

The cafeteria's leader, she knows that kids have allergies... So if one of these kids present to her and try to drink milk when they not supposed to, she will let me know right away.

Teachers had classroom responsibilities to prevent food allergic reactions, such as cleaning tables, checking labels on all children's snacks, and carrying the 'Epipen' on field trips. Most nurses reported that teachers were 'great about checking labels' on food packages. As one nurse said:

[We] have snacks, so I have to really rely and educate my teachers in the classrooms, so the teacher who has a food allergy in their room reads every label of every other kid's snack, every day. So if they have 20 students or 15, every snack they're reading.

Nurses did repeated outreach to teachers, as one nurse said, ‘I nail them down so that they don’t forget’.

Nurses reported that teachers usually cooperated with them:

The teachers are like peanut butter sniffing dogs. If they smell peanut butter in their class. They send the kids to me. They have to eat their lunch here with me wash their hands, wash their mouth before they can go back to the general population and then I’ll call those parents and really try to work with them to send something else.

In this narrative, it is apparent that there was an intricate web of actors involved in the management of food allergies. The details varied depending on the food allergy and the school’s policy, however, the work of generating collaboration from numerous actors was consistent across school nurses’ narratives. In addition to food allergies, this collaboration surfaced around other health related issues. Nurses also reported that teachers informed them when children brought unhealthy foods to school. For example, a nurse reported that a teacher told her about a child who brought processed cheese in an aerosol can as their lunch; the nurse then called the parents to inform them that this was not a healthy lunch. Another nurse said:

Some of the snacks that come in are really scary. I called a parent once because the child came in with six ‘Oreos’ [cookies] and a piece of cake. . . The teacher said, ‘This is what she brought in’. I called home.

School nurses hinted that occasionally school personnel resisted participating in enforcing school food allergy policies. As one nurse said, ‘Some teachers think they don’t have to check, that’s not their job. It *is*’. Although nurses claimed that it was the teachers’ responsibility to assist with food allergy management, teachers could opt out of certain responsibilities. For example, some teachers opted out of being responsible for administering the ‘Epipen’ on field trips. Even though not all teachers or staff whole heartedly joined in, from the school nurses’ perspective, their involvement was critical to securing adherence.

Unlike traditional adherence, the expectations for compliance extended well beyond patients and their caretakers to include non-ill children and their families. Examples of policies related to food allergies, other chronic conditions, and healthy eating policies exemplify the ways policies intended to protect the health of some students were applied to the entire school community. A crucial element of collective adherence was the pressure exerted on non-allergic children and their families to follow these policies. In order for food allergy management policies to be effective, the work of monitoring extended beyond school personnel. One nurse reported that teachers’ responsibilities were reduced once other school members acclimated to food allergy policies:

You check more in the beginning and then everybody gets on-board and is accustomed to no peanuts and nuts and that sort of thing. . . they [teachers] don’t check it [labels] maybe as closely because the children are now checking each other.

The ultimate goal was that all school members were aware of their food intake and food allergy related policies. This school-wide awareness was reinforced through policies, such as nut free classrooms or varying types of food tables, including special tables for children who had a lunch containing nuts. As one nurse explained, ‘there are a variety of tables they can sit at . . . everybody has to think – do I have any peanuts and nuts in my lunch?’ The expectation that everyone – not just children with food allergies – was thinking about what they are eating

was a sign of the successful implementation of a school's food allergy policy. This nurse concluded, 'I'm impressed with the children, they really are aware of what table they need to sit at with what's in their lunch'.

School nurses also reported other techniques for achieving high rates of adherence among children of the school, such as creating presentations and classroom activities that taught students about food allergies and ways of keeping food allergic friends safe. The goal, in promoting health, was not simply to educate individual children on managing their health, but recruiting all children to engage in behaviours that promoted the health of various children at the school. Through monitoring themselves and those around them, teachers, staff, children, and children's families collectively managed food allergies.

'Civil right if you like peanut butter'

Occasionally nurses recounted the difficulty of persuading parents of non-allergic children not to send children to school with certain foods and having to accommodate the needs of these non-allergic children. In Littleton Elementary, a school comprised of primarily middle-class students that instituted nut-free classrooms, School Nurse Sharon explained that she sometimes had to 'educate' parents:

We send home notes to parents asking them, again, 'It's your civil right if you like peanut butter, you can have it. We're just asking you not to have it in the classroom' and 99 per cent of people are very obliging because no one wants a child hurt, but you do sometimes have that one person that just won't do it. So then I may reach out and educate that person or we have to create an area where that child can have their peanut butter.

When parents of children who do not have nut allergies wanted to bring peanut butter sandwiches into nut-free spaces, schools had to accommodate them as well. Even with an allergy policy, or a nut-free zone, it was difficult for school nurses to prevent parents from sending in peanut butter sandwiches. Children who brought peanut butter to a nut-free school, however, typically had to eat in an isolated location.

Nurse Emily from East Side Elementary explained how Charlie's mother challenged the school's nut free policy:

You can't force them not to send the peanut butter. And I have had one parent actually challenge me, she called the superintendent's office and was like, 'well then you need to serve food that the kids like because my son doesn't like anything that's on the menu and all he'll eat is peanut butter'.

The administrators at East Side Elementary did negotiate with Charlie's parents about his bringing a peanut butter sandwich for lunch, however, they did not change their policy. Eventually, Nurse Emily 'made a deal with her [the child's mother] like he could bring 'SpaghettiOs' [canned spaghetti and tomato sauce] and I would heat them up for him every day'. Nurse Emily explained that she no longer heated Charlie's canned spaghetti and that he was bringing a different food for lunch. However, field notes during lunchtime observations show that he still brought in canned spaghetti that the school lunch staff warmed in the cafeteria microwave. Even without Nurse Emily's continued oversight, other members of the school community took on the work of creating compliance with the school's nut free policy. By helping to heat up Charlie's canned spaghetti they decreased the likelihood that he would

bring in peanut butter sandwiches, spared him from having to eat in the school nurse's office, and created a more equitable balance between the needs of children with food allergies and Charlie's dietary needs.

Balancing divergent needs

As in the example with Charlie's canned pasta, school nurses were not only managing available resources and liability concerns, they were also balancing a complex landscape of children's health and dietary needs. To implement policies, school nurses had to balance health conditions (i.e. food allergies), health risks (i.e. obesity) and the preferences of school members (i.e. children with limited diets, such as Charlie). Policies aimed to avoid negatively impacting children with health conditions, to improve health, and reduce overall risk.

'Kathy who's allergic to almonds, and Joey who only can eat almonds'

Even among children with food allergies, allergies varied and could be incompatible. One child's health regimen was not necessarily compatible with that of another. School personnel had to determine what foods could be brought into school and how to seat children during lunch. Nurse Sharon, whose school had an allergy table for children with life threatening food allergies, explained the complexity of keeping track of the allergies in the cafeteria:

Oh, my God, so now you sit down and you think it's a peanut butter sandwich, but it's that sun butter [sunflower seed butter that can serve as an alternative to nut butters], so this has become very tricky. On one hand, it's good, because now kids can have alternatives, but at that same table you have Kathy who's allergic to almonds and Joey who only can eat almonds. So our table is changing. . . Also the right to privacy, you can't tell every person what that kid is allergic [to].

Alternative foods, such as almond butter or sunflower seed butter, enabled children to have a more varied diet, which was important to parents of children with food allergies who sometimes reported difficulty finding safe alternatives. From the school's perspective, these foods made it more difficult to manage multiple allergies. One of the challenges of managing food allergies in schools was that children were diagnosed with different and often multiple food allergies. Thus, policies needed to be inclusive of different allergens and also accommodating of the different types of foods that children wanted to eat at school.

In addition to concerns about food allergies, schools also had a healthy eating policy in the school districts where I interviewed nurses. Often these food-related policies were coordinated, a concern that some parents expressed in interviews.⁴ Sheila, a nutritionist and mother of a child with a milk and egg allergy, reported to me that she had concerns about the 'approved snack list' for her son James' classroom:

The approved snack list that's allowed in his room I do have issues with because they are calling it a 'healthy' snack list because they are trying to roll the [allergy policy into] the school wellness policy. They're trying to roll this into that. And this healthy list has on it – Cheez-Its [brand of cheese crackers], which aren't healthy. And it's fine if kids want to eat Cheez-Its, but don't label them healthy!

For Sheila, her primary concern was giving her son healthy foods that contained sufficient fat and protein, particularly because he could not eat egg or dairy. The school policy, however, favoured nut-free and low-calorie foods.

Many of the schools included in the sample were limiting the types of foods that could be given at celebrations or becoming food-free. Food-free policies were aimed at reducing the risks related to obesity and other health conditions requiring that children managed their food intake. Food-free policies involved modifying school traditions that had previously involved food items. One nurse explained:

We have one class, one group that goes on a field trip, it's a lovely little field trip, they go to the post office and they go to the library and then they go to the ice cream store in town. Nice little ice cream store. And I say they can get a gift certificate at the ice cream store to go back with their parent and enjoy whatever.

This nurse modifies this longstanding field trip to reduce the risk that a child will be exposed to an allergen or unable to participate in the school activities because they could not eat the ice cream. For example, another school nurse recounts learning of a food allergic child feeling excluded from a class breakfast:

At the breakfast there were things that were brought in that were maybe homemade and so an allergic child can't really have that because you don't know if there was cross-contamination in the preparation of it, but I think they made the effort not to use the ingredients, but still there wasn't anything her child could have.

It was not just the needs of food allergic children, but of children with dietary needs that required school-wide policies to secure collective adherence. In another example, a child with type-1 diabetes was impacted by the violation of the food-free policy. One school nurse recounted:

My diabetic [child] comes running down two in the afternoon and she said, 'I need some insulin'. I said, 'What do you mean?' And she said, 'We're having ice cream in our classroom'. I said, 'No, you're not honey. We're food free'. She said, 'No, we're having ice cream'. I went up there and they had these canisters of leftover ice cream and they're dishing it out. I went ballistic, I have to say. I called my supervisor, I said, 'Here this is requiring this child to have more insulin'. She [my supervisor] called the superintendent.

Securing collective adherence involves implementing policies that were intended to help some individuals, but did not always meet the desires of the group. Monitoring the insulin intake of this child was critical for her health:

Her blood sugar would be sky high. She needed the insulin to cover. And she was a child that she needed – mom did tend to give her a lot of carbs for lunch, so she had a lot of insulin so now she has a lot of insulin on board in the pump you're giving her more insulin. She's riding the bus home. When it's a medical issue, you don't fool with that.

These policies were aimed at managing health conditions, the risk of a health condition, or ill health (Aronowitz 2015, Conrad and Waggoner 2017). Implementing the policies and eroding

longstanding traditions required significant effort on the part of the school nurse. Nurse Mary described reprimanding teachers that violated the food-free policy at a book group meeting:

I go to the book group, this happened about a month ago, six weeks ago, and I go in and we're talking there are donut holes and hot chocolate at 8 o'clock in the morning. I said, 'No food. No food'. [They said] 'Mary, please, don't be a wet blanket'. I'm like why would you give – and first of all did the parents know you're giving children donuts and hot chocolate at 9 in the morning? What message does that send?... It's not helpful. This one little somewhat overweight little boy next to me is just downing those and I'm like, what did you do to him this morning. You can't do that. You can't do that. It's no longer acceptable you know.

In this instance, the nurse framed the school's food-free policy largely around the issue of reducing the risk of childhood obesity, particularly for children who were already overweight. Yet these food-free policies were also intertwined with food allergy management and diabetes management.

Children who were allergic to multiple foods, the school's healthy eating initiatives, and other health conditions requiring special diets resulted in competing prescriptions to be followed in the same setting. The multiplicity of needs created challenges for school personnel who had to manage these needs and the discontent of families that were asked to adhere to numerous health-related policies.

Discussion

Drawing from in-depth interviews and selective school observations, I argue that *adherence* can be collective – meaning that decisions about treatment are dynamic, negotiated, and enforced by numerous actors, including those affected by the illness and those living beside them. Unlike traditional adherence, which researchers have conceptualised as a relatively individualistic endeavour involving either patients and doctors or patients and their close ties, adherence to lifestyle conditions hinges upon the work of numerous community members and medical providers. The work of illness management extends beyond patients, their close ties, and medical providers. Previous studies have underemphasised negotiations and changes in medical recommendations, the interplay between different medical providers, and the potentially conflicting needs of illness and non-illness sufferers who inhabit the same institutions.

In this paper, I propose the concept of 'collective adherence' to capture these understudied dimensions. I identify three features of how school nurses secured collective adherence in schools. First, school nurses interpreted a medical recommendation and negotiated an alignment between school members, physicians, and families, which included parents and children. Actors who advocated for a more risk-averse treatment plan tended to wield more influence over the final decisions. Second, school nurses imposed a set of protocols on multiple actors in the school community in order to secure the health of the school children with food allergies. Public caregivers and non-ill families were involved in managing children's health conditions and asked to adhere to recommendations. Third, school nurses balanced the conflicting needs and interests of different school members in an effort to manage health conditions and health risks.

A limitation of the concept of collective adherence is that there is likely variation in the degree of collective adherence that different conditions garner, with conditions involving lifestyle changes or environmental triggers presenting more opportunities for collective adherence.

Yet there are signs that more individualistic treatment plans, such as those for epilepsy, also require negotiation of the treatment plan between nurses and physicians and families in order to balance individual needs and institutional constraints (O'Dell *et al.* 2007). Also, this study may underestimate the role of children as actors because younger children are less involved in allergy management than older children. By selecting families with food allergic children under the age of 12, the sample overestimates the role of caretakers in managing food allergies and limits the visibility of children's work, which increases in the adolescent years. Future research should examine whether the concept of collective adherence is useful in depicting the ways that caregivers play a mediating role in adult patients' adherence, such as in the case of chemical sensitivity syndrome (Zavestoski *et al.* 2004).

A critical component of this study is the finding that the medical recommendation was not a static entity nor did it originate from one source – the doctor. School nurses, both in setting school allergy policies and in 'real time' responses to allergic reactions, interpreted doctors' recommendations and made their own recommendations. These findings suggest that adherence is not simply a matter of following static directives from a singular health provider. Further study is needed to examine the prioritisation of recommendations when there are multiple providers involved. Other studies show that in clinical settings, nurses defer to doctors' orders even when they know that the orders are incorrect or should be modified; they use covert methods to encourage doctors to make correct prescriptions (Allen 1997). In the school, however, the nurse-doctor relationship is less clearly defined. The medical recommendation is in writing, but the doctor is not within the same institution and does not have the same hierarchical relationship with the nurse that exists in clinical settings. Further research should examine whether this distinction contributes to role ambiguity (Lightfoot and Bines 2000, Merrell *et al.* 2007, Reuterswaid and Lagerstrom 2010). Also, the school has particular constraints that are different from the more bounded constraints that exist within a clinical setting. Further examination of the interplay among medical providers and providers working in non-medical environments and the impact on the management of illness is needed.

One consequence of extending the study of adherence beyond the patient-doctor dyad is that the labour of securing adherence among multiple actors is highlighted. A significant amount of the work that school nurses did to create a smooth-running system for food allergy management occurred behind the scenes and was invisible to the parents in the study. That parents in the study were unaware of this work suggests that the work that others do to assist with adherence may not be accessible through patient narratives. By examining food allergy management from the perspective of school nurses, this paper also contributes to the call by Murdoch *et al.* (2013) for a more nuanced examination of patients' talk about adherence and its meaning.

The challenges that school nurses faced in balancing the needs of children with food allergies and the needs of other families and children at the school is distinct from the challenges that illness sufferers faced in managing their close relationships, which others have already identified as a key factor shaping adherence decisions (Conrad 1985). By examining the school nurse, different dynamics are exposed. For example, as nurse interviews show, the school nurses took on the dual role of medical provider and caregiver responsible for securing adherence (see also Rous and Hunt 2004). This latter role is one that parents or other caretakers typically adopt on behalf of children or others who cannot care for themselves (Timmermans and Buchbinder 2012). Future research should examine the gendered dimensions of this dual role and whether it is more prominent among nurses working outside of the medical setting, such as schools and home care environments.

While nurses were challenged by the diverging needs of different actors at the school, including the allergy patient and their family, they also wielded considerable authority in

determining the terms of school attendance for children with documented food allergies and the treatment of food allergic reactions. Nurses' authority is illustrated in the example of the high school nurse who administered 'Epipen' to a young girl with a peanut allergy without her parents' consent. Researchers have identified a shift toward greater patient control and empowerment, namely the rise of the 'patient consumer' (see Barker 2008, Conrad and Leiter 2005, Henwood *et al.* 2013). While the concept of the patient consumer is a helpful characterisation of doctor-patient interactions in private or pay for service medical settings, in state-run institutions with limited choices, patients may continue to find medical authority undiminished (see also Pilnick and Dingwall 2011). Findings from the larger study show that parents of children with food allergies had more flexibility in interactions with physicians, by changing doctors for example, than in interactions with school nurses (Muñoz 2014). In interactions between school nurses and parents, nurses still had considerable authority over parents when responding to allergic reactions and enforcing school protocols, such as bringing in 'Epipens'. Parents could not easily change schools or school nurses to obtain a different set of protocols as they could in doctor-patient interactions by change physicians or in their own personal lives by modifying treatment regimens.

Despite the relative rigidity of bureaucratic institutions, such as schools, parents wielded varying levels of influence over school decisions. Of particular note is the interplay between the social class of parents and the risk-aversion that each parent exhibited. Villalobos's (2014) study of risk and parenting similarly did not find significant social class differences in whether mothers adopted a risk-averse or risk-seeking approach to childrearing. Since it is well-documented that highly educated parents are more likely to make requests of institutions (Lareau 2003/2011, Lareau and Muñoz 2012), it is likely that among the most risk-averse parents, the middle-class parents were more vocal and insistent in their requests, therefore, exercised greater leverage over school decisions. For example, parents in a school consisting of primarily middle-class parents requested that the school become 'nut-free' despite resistance from the administration (see also Frost and Chalin 2005).

Further examination of non-traditional medical settings, such as school health centres, and the role of caretakers, such as childcare providers and home health assistants, is needed to enrich our understanding of patient decisions and the management of illness. By considering the collective element of patient adherence, this paper highlights the ways that medical decisions are made in non-medical settings and the role of ancillary medical providers, such as school nurses, in negotiating these medical recommendations. Others have called for further elaboration of the social processes of risk management that food allergy management exemplifies (Nettleton *et al.* 2009, Stjerna *et al.* 2014). I propose that collective adherence is one such mechanism through which these social projects of risk management are enacted within institutional settings.

Address for correspondence: Vanessa Munoz, Colorado College – Sociology, 14 Cache La Poudre St, Colorado Springs, Colorado 80903, United States. E-mail: vmunoz@coloradocollege.edu

Acknowledgements

Author thanks Elizabeth Coggins, Peter Conrad, Annette Lareau, Mateo Muñoz, Wade Roberts, Jan Thomas and Manya Whittaker for feedback, the anonymous reviewers for their thorough reviews, and colleagues in the sociology departments at Colorado College and Brandeis University for their comments and support over the years.

Notes

- 1 In response to high rates of non-adherence, the Pharmaceutical Society of Great Britain proposed the concordance model, a clinical encounter in which patients and doctors negotiate a treatment plan (Bissell *et al.* 2004, Chatterjee 2006, Cushing and Metcalfe 2007, Segal 2007).
- 2 In accord with this shift, school nurses' efficacy is typically measured through emergency preparedness and case management, improving outcomes associated with chronic health conditions (Bonaiuto 2007, Borup and Holstein 2010, Guttu *et al.* 2004, McCarthy *et al.* 2000, Olympia *et al.* 2005, Taras *et al.* 2004).
- 3 The cost of the 'Epipen' was about US\$120 and all schools in the study required that children with food allergies keep at least one 'Epipen' at the school in case of an emergency. Some schools also had an extra 'Epipen' for unknown allergies or other unexpected events. The cost of the hospital visit would typically begin at \$150 per visit. In the US, where 60 per cent of people were covered by private health insurance in 2012, visits to hospitals typically require a co-payment or cost-sharing from the patient.
- 4 It is important to note that the sample in this study likely underrepresents parental discontent because parents involved in the study all had children with food allergies.

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