

# **What has been preventing the emergence of a broad social movement on diabetes (and NCDs)? Insights from the mobilisation of diabetes patients' associations in Bamako, Mali\***

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## *Abstract*

Non-communicable diseases (NCDs) are among the leading causes of morbidity and mortality globally. While international strategies for their prevention and control call for greater civil society participation, many observers regret the lack of a broad social movement to address these diseases. This study focuses on diabetes patients' associations engaged from 1991 to 2014 in Bamako, Mali, and explores what factors influenced their capacity to build a collective national movement to address this disease and shape policy reforms in this area. Our findings show that the emergence of such a movement was limited by several constraints. The focus of diabetes patients' associations on technical biomedical issues silenced the daily embodied experience of patients and reduced the use of human-rights approaches. Moreover, few financial, material and social resources coupled with a fragmented base limited the scope and strength of claims made by patients' associations to obtain treatment at reduced costs. Finally, modes of actions performed failed to challenge more structural inequalities and imbalances of power. Exacerbated by limited political opportunities, these constraints weakened the associations' ability to drive policy change on diabetes. They reflect some of the current weaknesses of the global mobilisation to address diabetes and NCDs.

*Keywords:* diabetes; non communicable diseases (NCDs); patients' associations; health social movements; Mali.

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## **Introduction**

Non-communicable diseases (NCDs) are among the leading causes of morbidity and mortality globally (Roth et al., 2018; Vos et al., 2020, p. 376). WHO's strategies for their prevention and control call for civil society organisations to participate in policy development, resource mobilisation, information dissemination, advocacy and accountability (WHO, 2013, 2018, 2019). Still, to many observers, social mobilisation remains very limited in this area. In 2011, the then CEO of the International Diabetes Federation regretted that, compared to the HIV/AIDS movement, 'the NCD movement still has work to do to ensure that people with diabetes and NCDs are involved at all levels' and called 'people with these diseases to stand up and demand their right to health and to universal access to medicines' (Keeling, 2011, p. 164). More recent reports and studies come to the same conclusion. The Global coordination mechanism on the prevention and control of NCDs complains of 'delays in creating a multi-stakeholder social movement to address NCDs' as a whole (WHO, 2018, p. 15). According to an article addressing the process of prioritisation of NCDs at global level (Heller et al., 2019), despite the advocacy work done by the NCD Alliance since its creation in 2009, 'civil society movements behind the four main diseases [cancer, cardiovascular diseases, chronic respiratory diseases, and diabetes], remain relatively fragmented and weak' (p. 376).

This concern for the engagement of civil society organisations in general and social movements particularly acknowledges the role they have played in addressing a variety of global health issues, such as HIV/AIDS, women's health or breast cancer. Their engagement has empowered lay people with medical information, promoted self-care and self-help, and progressively led to changes in healthcare delivery, research and policies (Brown et al., 2011; Brown & Fee, 2014). This is why Brown and Zavestoski

(2004) define health social movements as ‘collective challenges to medical policy, public health policy, belief systems, research and practice’ (p.679).

Four main lines of analysis emerge from literature on social movements. The first relates to the collective and temporal nature of such movements. According to Tilly (2004), collective claims on targeted authorities involve different parties whose interaction is sustained and goes beyond any single event. This implies considering what groups and individuals engage in social activism (Crossley, 2002), as well as the context in which events and processes occur, their duration, trends and cycles (Tarrow, 1993). The second line of analysis relates to collective action frames, i.e. the ‘schemata of interpretation’ (Goffman, 1986) which form the rationale behind the engagement of a social movement. For Snow and Benford (1988), social movement organisations define problems, solutions, and motivations through framing processes that shape the movement’s cause. The resulting frames may change over time and intra- and inter-organisational disputes may occur (Benford, 2013). A third line of analysis relates to the resources upon which social movements can draw. These include the movement’s base and its structure (McCarthy & Zald, 1977), financial resources, expertise and leadership (Grossman & Saurugger, 2006), relationships with stakeholders like public authorities, medical and private actors (Mathieu, 2012). The fourth line of analysis concerns the modes of action (petitions, media declarations, demonstrations, etc.) that movements perform to pursue their goals and make collective claims. In this regard, Tilly’s notion of ‘repertoire of action’ recalls that people use actions available to them, such as what they know and what they are expected to use, in a particular context (Tilly, 1978).

Extensive literature deals with social movements that have emerged all over the world in relation to communicable diseases and notably HIV/AIDS (Barbot, 2002; Broqua, 2018; Eboko et al., 2011; Epstein, 1996). Social movements on NCDs have

been mostly studied in high-income countries and in relation to asthma and breast cancer (P. Brown et al., 2004). With respect to diabetes, a systematic review on how qualitative methods have been used in over 30 years of international diabetes research shows that this issue has been mostly explored in a medical perspective within the framework of individual patient-doctor relationships and self-care (Hennink et al., 2017). Literature related to African contexts pays particular attention to social representations of diabetes (A. de-Graft Aikins, 2002; A. de-Graft Aikins et al., 2012; Mshunqane et al., 2012; Mwangome et al., 2017; Rutebemberwa et al., 2013) and patients' experience of their illness (Amoah et al., 2018; Ama. de-Graft Aikins, 2003). These articles mainly explore factors that influence illness action at individual level and aim to suggest strategies for diabetes intervention at community level (A. de-Graft Aikins et al., 2015). What has been generally neglected is a macro and more political approach focused on collective action performed by civil society organisations and its impact on public policies to prevent and manage diabetes. At an international level, Chaufan and Saliba (2019) adopt a political economy lens to study how discourses and practices of three non-profit organisations fighting against diabetes (in Canada, the United States, and at international level) have influenced global health strategies and the reduction of health inequities. A few additional studies explore collective action on diabetes by comparing interventions made by different single-disease associations. Best (2012) studies how advocacy groups addressing a total of 53 diseases have influenced medical research priorities in the United States. An article comparing how different stakeholders engaged to fight chronic diseases in Ghana and Cameroon mentions the work done by the Ghana Diabetes Association but analyses it together with associations addressing other NCDs and comes to global conclusions (A. de-Graft Aikins et al., 2010). In the same line, Heller and colleagues (2019) give some information on how the

NCDs Alliance, including the International Diabetes Federation, has contributed to the process of prioritisation of NCDs at global level; their focus is however more general on agenda-setting than on social mobilisation per se.

A similar trend can be found in studies carried out on diabetes in Mali. Here the issue has been mostly studied from an epidemiological (Fisch et al., 1987; Imperato et al., 1976) and a biomedical perspective (Beran & Yudkin, 2010; Besançon, 2009; Pichard et al., 1988; Sidibé et al., 2000). Anthropological research focuses on lay knowledge and practice of patients and health professionals (Gobatto & Tijou Traoré, 2011; Tijou Traoré, 2010, 2017), and attention is given to self-care and the way it has been supported by either public policies (Gobatto et al., 2016) or NGO programs (Besançon et al., 2016). The few articles about collective action implemented by civil society remain mainly descriptive of the story and work done by single organisations like the first patients' association (Besançon, 2006) and a French non-governmental organisation (NGO) (Besançon et al., 2015; Besançon & Sidibé, 2012; Besançon et al., 2018). A broader political approach is taken by Martini and colleagues who study how different stakeholders have contributed to put diabetes into the policy agenda of Mali (Martini & Fligg, 2011; Martini et al., 2019b) and what contextual political opportunities have shaped the participation of patients' associations to the fight against diabetes over time (Martini et al., 2019a).

This article aims to broaden and deepen the knowledge on how collective action on diabetes was developed by patients' associations in the context of Mali. It does it by drawing on a social movement perspective and the four lines of analysis mentioned above. After tracing the history of patients' associations that engaged to address diabetes in Bamako from 1991 to 2014, it investigates how they framed their engagement, upon which resources they drew, and which actions they performed. In

doing so, it explores what factors influenced the capacity of patients' associations to build a collective national movement and to shape policy reforms addressing diabetes (and NCDs). It gives insights into what may have limited the emergence of a comprehensive social movement related not only to diabetes but also to NCDs at global level. For this reason the case of Mali is interesting for the scope of this article.

### **Material and methods**

Mali is a low-income country ranked 184 out of 189 countries according to the last human development index (UNDP, 2020). It remains highly dependent on international donors, who funded about 45% of the health budget during the period studied (MHPH et al., 2014). At least until the military coup of March 2012, the country was considered by most donors as a success story of democratic transition in Africa (Wing, 2002). After the democracy was established in 1991, the number of civil society organisations, NGO, political parties and medias rapidly increased (Raghavan, 1992; Thiriou, 2002). This growth was related to the liberalisation of political life (Wing, 2013) but also to the support that international donors provided to civil society with the aim of promoting good governance (Roy, 2010). In all cases, it did not result in increased conflicts and the country was most known for its weak protest tradition (Siméant, 2014). Like other Sub-Saharan African countries, the Malian health system has long been directed towards the prevention and control of infectious and acute diseases (Beaglehole & Yach, 2003). Yet, cases of diabetes were reported in Bamako and rural areas since at least the 1970s (Imperato et al., 1976). Since then, the country has been ranked as one with low diabetes prevalence, which was recently 1.9% according to the International Diabetes Federation (IDF, 2019). However, accurate data is still missing, and local studies report a higher prevalence rate of about 9% (MHPH, 2014). In terms of patients' associations,

Mali has experienced an early mobilisation around diabetes and has long been one of the few in West-Africa to host a community centre specialised in diabetes care (Besançon, 2006).

This research was conducted in Bamako, where both the first diabetes patients' association and community centre are situated. Bamako is the political and economic capital city of Mali and concentrates most university hospitals and specialised care services. In the early 2000s, diabetics patients from all over the country came here for treatment, notably in the community centre for diabetes care and in two hospitals where the only diabetologist of the country and one endocrinologist worked. A decentralisation strategy for diabetes care was started only at the end of the 2000s through ongoing training of doctors and nurses working in secondary health centres. Among them, the health centres situated in the 6 municipalities of Bamako.

Field surveys were conducted in 2008 (12 weeks), 2010 (3 weeks), 2012 (2 weeks), and 2014 (1 week) by the first author. This was done in the framework of successive projects to which the first author initially participated as an intern and then as a researcher and PhD student. Some of the projects were coordinated by the second author and the PhD was supervised by the third author. Carrying out the research over a long period of time allowed to retrace the history of diabetes patients' association in depth and to study their development in its making. It also involved a series of challenges. They were related to the expectations that local stakeholders had from the research project, which increased over time in parallel with the increased attention given to diabetes at international level. The research was welcomed at the beginning by the few local stakeholders engaged in diabetes at the time, who saw it as a mean to let their cause be known internationally. Over time however, the arrival of some international funding and the creation of new patients' associations came along with increased

tensions among local stakeholders and let it more difficult to obtain interviews and spontaneous speeches from the interviewees. At the end of the research, further challenges related to contextual changes and notably the sudden political and security instability meant that it became too difficult to conduct field surveys and delayed the final restitution that had been planned in Bamako with key stakeholders.

Data collection was carried out by means of qualitative interviews and non-participant observations. Interviewees and events were identified by document and internet searches, as well as by a snowball method that involved identifying new persons or events through key informants. All in all, 55 stakeholders were interviewed among those involved in the health sector and the fight against diabetes like representatives of international donors (17), NGOs (16), national public servants (9), patients' associations (8), and health professionals (5). In line with its scope, this paper focuses on data collected from the representatives of patients' associations. Their point of view and their role of spokespeople make them key players in framing the identity, scope and activities of the associations they are representing (Hassenteufel, 1991). In this case, they represent 6 out of the 7 diabetes patients' associations that are based in Bamako. In fact, only one association could not be met, due to organisational and time constraints. As table 1 shows, they span three stages of the mobilisation around diabetes and some representatives were met several times over time.

*Tab. 1. Representatives of diabetes patients' associations interviewed.*

|  | 2008 | 2010 | 2012  | 2014 |
|--|------|------|-------|------|
| <b>First-stage association<br/>(1 out of 1)</b>  | A    |      | B     | B    |
| <b>Second-stage association<br/>(1 out of 1)</b> | C    |      | C     |      |
| <b>Third-stage associations<br/>(4 out of 5)</b> |      | D    | D + E | D    |
|  |      |      | F     | F    |
|  |      |      | G     |      |
|  |      |      | H     |      |

*Source: by authors. Each line represents a single association; each letter identifies an interviewee. The label used to identify the association refers to the stage of the mobilisation on diabetes when the patients' association was created.*



All interviews were conducted in French and face-to-face by the first author, either at the interviewee's home, the association headquarter or the health facility. Verbal consent to participate was always obtained at the beginning of the interviews, which were recorded upon agreement. The interview grid covered the following themes: the association's history, its goals and missions, its organisation and partnerships, the activities performed, lay knowledge and its use. Data were supplemented by non-participant observations conducted for example during visits in the health centres or events organised for World Diabetes Day and which allowed supplementary informal exchanges with the stakeholders. Documentary sources were also collected, including policy documents, activity reports, and advocacy tools.

Concerning data analysis, all interviews were transcribed and analysed inductively. A vertical analysis of each single interview was performed; information collected from different sources was then triangulated through a horizontal analysis of each theme coded. The analysis was progressively refined with the new data collected in successive surveys (Bazeley, 2013). Data collection was stopped when no new themes and no significant increase in the sophistication of analysis emerged (Saunders et al., 2018). The thematic analysis explored the four lines of analysis associated with social movements: the collective and temporal nature of patient associations' mobilisation, their collective action frames, resources available, and actions undertaken. The frame analysis aimed to understand how patients' associations constructed problems, solutions and motivations in order to raise engagement around diabetes (Benford & Snow, 2000).

## Results

### *The collective and sustained mobilisation around diabetes*

From 1991 to 2014, patients living with diabetes in Bamako gradually gathered to create seven patients' associations and two coordination mechanisms at regional (district) and national level respectively. This collective mobilisation went through three main stages, each being marked by specific contexts and trends (fig.1).

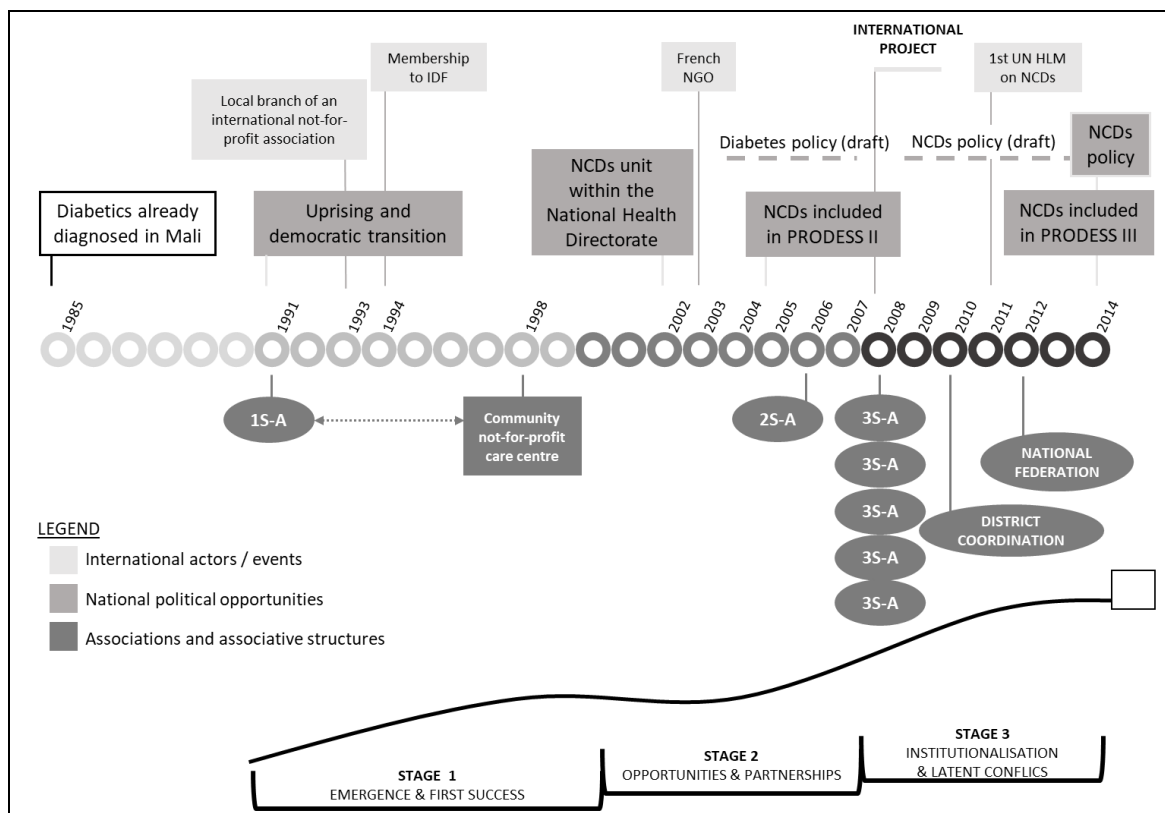


Fig. 1. History of the mobilisation of diabetes patient associations in Bamako. Source: by authors.

The first stage started when local patients supported by the only diabetologist of the country founded the first diabetes association in 1991. Their mobilisation played a pioneering role in the fight against diabetes. At policy level, diabetes did not figure in any strategy and no department tackled NCDs. This stage peaked in 1998 when the association opened a community non-for-profit centre for diabetes care, the first of its

kind in Mali and among the few in West-Africa at the time. For more than a decade this remained the only association specifically dedicated to the fight against diabetes, as its label indicated. Despite the fact that doctors were members of its board, it was generally presented as a patients' association. Its headquarter being in Bamako, it tried to promote local branches in other regions of Mali.

The second stage at the beginning of the 2000s was one of renewed political opportunities and partnerships. For the very first time, NCDs were addressed by the National Health Directorate and included in the social and health program (PRODESS II); the drafting of a diabetes policy was also initiated. At the level of civil society, a French NGO started to provide technical assistance for the prevention and control of diabetes in Mali, including for the decentralisation of diabetes care in the six municipalities of Bamako and outside the capital city. As detailed below, these interventions inspired the creation of a second association in one of Bamako's municipality. The label it chose specifically targeted it as a patients' association.

The third stage between 2008 and 2015 saw important changes. The diabetes policy draft was included in a more comprehensive NCD policy, whose elaboration was initiated in 2009. The Malian prime minister participated in the United Nations High-Level Meeting (UN-HLM) on NCDs held in New York in 2011. Concerning diabetes, five additional patients' associations were created in the five remaining municipalities of Bamako where a diabetes unit had also opened its door. They were also specifically labelled as patients' associations. The collective nature of their mobilisation was further institutionalised through the creation of a regional coordination in Bamako in 2010 and of a national federation in 2012. Two years later, the latter brought together about 25 patients' associations across Mali. Despite these achievements, latent conflicts emerged.

Hereafter motivations, resources and forms of actions that characterised the associations engaged in Bamako are presented more in depth.

### *How did the associations frame their mobilisation?*

The gradual engagement of diabetes patients relied on collective action frames that were slightly different from one stage to another depending on the existing health system context.

At the first stage, problems were identified in service provision and the solution was sought in the engagement of those patients (and doctors) willing and able to campaign for the opening of a community non-for-profit centre. As a patient representative recalled in 2012, the overarching goal was ‘to have a place where to treat all diabetics of Mali, because all diabetics of Mali came to doctor [name], with a small office’<sup>†</sup>. The association creation fell in the aftermath of the democratic transition, when civil society started engaging in all areas of society. Members’ motivation built on a pragmatic and disenchanted approach about Malian state’s (in)capacity to give them support. As the representative continued, ‘The authorities gave us this old building [...] we looked for a partner because the minister had been clear, he said they had no means to renovate it and, even less, to give material’. Another representative said in 2008, ‘Only the good will can help the poorest to have appropriate care, since the state cannot ensure full coverage of [...] a disease’.

Access to care was still a key concern for the association created in Bamako during the second stage of the fight against diabetes in the mid-2000. A representative described in 2008, ‘only one diabetes centre exists here in Bamako, people must travel

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<sup>†</sup> Translated from French by authors.

[...] to seek care [...] not only it's far, but it is expensive too'. However, solutions were linked to the decentralisation process that Malian government had initiated with the support of the French NGO. As recalled by the association representative in 2008, 'I wondered whether it would not be better with a patients' association' [within the premises of the municipal health centre]. In particular, the association was motivated by the possibility of implementing projects funded by the French NGO to facilitate patients' access to diabetes care at municipal level.

During the third stage at the end of the 2000s, the creation of five additional associations reveal collective action frames similar to those of the second-stage association. The new associations pointed to problems related to service provision and linked solutions to the ongoing decentralisation process. Each association also worked closely with the health centre of a specific municipality of Bamako. Contrary to the second-stage association however, motives did not result from an endogenous process. In fact, their creation was a direct output of an international project funded from 2008 to 2010 by a consortium of international NGOs. A patient representative recalled, 'They gave us the idea to build. [...] The project manager [...] came to us' (2012).

During this last stage, two main problems related to diabetes management were similarly framed by all representatives, regardless at which stage their association was created. First, the problem of access to care was now related not only to geographical difficulties but also to financial costs. All described diabetes as a 'disease *for* rich people' due to high treatment costs, thus contesting the longstanding view of diabetes as a 'disease *of* the rich'. Second, little awareness among the population and little adherence of patients to diet and physical activity were considered problematic in the fight against the disease.

### *What resources were available to the associations?*

This section presents three specific resources available to patients' associations: their mobilisation base, their social resources, their material and financial resources.

Concerning the mobilisation base, the internal cohesion of each patients' association was limited by two main shortcomings. First, although the associations officially counted between 100 (for some municipal associations) and 3000 members (for the first-stage association), most ordinary members were depicted as passive adherents with little will and ability to engage actively. Overall, they were mainly involved as health-care users. The use of membership cards shows this last point: they were delivered to allow care at reduced costs more than to create a sense of community. Secondly, all representatives had a high socioeconomic and educational status, while ordinary members were mostly low-income patients. Representatives' discourses mirrored this distance from the associations' members. The latter were referred to using the third person and diabetes' patients were generally described as being undisciplined because of their poor adherence to treatment, although most representatives also lived with diabetes.

Still exploring the mobilisation base, but now looking at the relationships between diabetes associations, the second stage was a period of renewed partnerships, since links were sought between the first- and second-stage associations. Yet, with the emergence of additional municipal associations and the greater institutionalisation during the third stage came tensions. These tensions may be linked to the scope of each association and to the difficulty for the first-stage association, which pursued a national scope, to fit the newly formal structure organised into local, regional and national levels. These tensions may also be explained by struggles for legitimacy, each

association claiming it on the basis of either its temporal coverage, local or international roots.

Regarding the social resources, partnerships established with external actors were mostly based on personal ties that board members had, notably with local private stakeholders or Malians living abroad, notably in France. These partnerships however highly depended on the good will and availability of such donors. More sustained partnerships were established by the first-stage association with a local branch of an international not-for-profit association and with the IDF; while the municipal associations, including their organisation into a regional coordination and a national federation, were supported by the French NGO. These partnerships however mostly targeted specific initiatives, such as the renovation and functioning of the diabetes care centre, World Diabetes Day, or projects funded by the French NGO. Furthermore, all associations were closely linked with health professionals. As said above, caregivers were among the founders of the first-stage association and seated in its board. Moreover, during the 1990s, French doctors helped the association to train caregivers working in the diabetes centre and outside Bamako. The second and third-stage associations closely collaborated with health professionals working in the municipal diabetes units for the implementation of prevention and education activities. All associations also established links with pharmaceutical representatives, since they offered treatments at reduced costs. In all cases, partnerships were strictly focused on diabetes. Despite the absence of partnerships with organisations and movements addressing other health issues, diabetes associations were inspired by them in terms of goals to pursue and actions to undertake, ‘We really want care to be free, like it is for malaria, tuberculosis and HIV/AIDS’ (second-stage association, 2008); ‘Why care is free for them? Because [people] formed a group!’ (third-stage association, 2010).

Concerning material and financial resources, all associations faced several constraints over the three stages. Membership fees provided all associations with some revenue, but not without difficulties, 'Often people say: we pay later, but we wish to adhere!' (a representative of the second-stage association, 2008). Aside from the important funding received for the renovation of the care centre premises, the first-stage association received mostly occasional financial and material donations (mainly drugs and treatments). Its membership to the IDF provided with campaign materials and opportunities to participate at international fora and trainings; however, not only did this support mainly revolve around World Diabetes Day, but it often targeted caregivers more than care-receivers. The second and third-stage associations mainly depended on the French NGO and particularly on the funding that the latter obtained from international donors to implement activities and fund infrastructures and materials.

### ***What actions did the associations perform?***

The modes of actions performed to address diabetes show that patients' associations mainly engaged in care and awareness activities, while being only occasionally involved in policy process, overt advocacy, demonstrations, or research.

Concerning their involvement in policy processes, the lack of any official policy during the first stage limited contacts with the Ministry of Health, which mainly revolved around administrative issues related to the centre for diabetes care. During the second stage, the drafting of a diabetes policy offered a seat at the table to the first-stage association; however, the policy support was mainly delegated to a doctor among the association's founders. During the third stage, the first-stage association attended a preparatory meeting for the UN-HLM in New York thanks to funding from IDF; however, it was little involved in the drafting of the Malian NCDs policy. In this



respect, the second- and third-stage associations were mainly represented by the French NGO.

In terms of advocacy, the regional coordination gathering the municipal patients' associations sent a letter to the Ministry of Health and the Ministry of Social Development respectively in 2010; material and financial support was demanded for members of the municipal associations, including free tests, insulin, and treatment for diabetes foot. Further advocacy, however, was not undertaken, 'We wait now before contacting other policy-makers, to influence their decision, since those we wrote to haven't replied (third-stage representative, 2010).

Activities like demonstrations and public speaking were mostly held on World Diabetes Day. On this occasion, all associations aimed to raise awareness among the population and to draw the attention of local and national authorities. Patients' representatives participated on radio or television programs at national level. Awareness activities were also organised within the health centres premises, notably education activities and to a lesser extent testimonies of the daily embodied experience of patients. Distinguished guests were invited, like the First Lady in 2010 or the Prime Minister in 2012. And public marches were held either at municipal level or through Bamako, like the march to Parliament organised in 2009 by the first-stage association. These marches included bands and overt protests never took place. The scope of the claims focused on access to care delivery and did not address social inequalities in health nor human rights.

Finally, the associations engaged in little research. Overall, patients' expertise was rarely spotlighted nor used to challenge medical knowledge and practice. The first peer educator activities started in 2011, following the support of the French NGO to the second and third-stage associations. On the other side, representatives' discourses about

diabetes and its management largely aligned on technical and clinical recommendations, blurring the frontiers between lay and scientific knowledge.

## **Discussion**

This article has applied a social movement perspective to explore why and how patients living in Bamako engaged in collective action to address diabetes between 1991 and 2014. It has identified which different associations and collective structures were created over time; it has explored how they framed problems, solutions, and motivations to engage; it has analysed the resources available to them and the actions they performed. This approach centring on collective action developed by patients' associations is new in the study of the fight against diabetes in Mali and has been relatively little used in other contexts. A previous study on Mali showed that limited external political opportunities had negatively affected the associations' capacity to participate in policy processes on a regular and ongoing basis (Martini et al., 2019a). This paper took the other end of the spectrum by exploring the endogenous processes that underlaid the development of patients' association and their capacity to build a strong collective movement able to influence policy reforms addressing diabetes (and NCDs). This shed light on dynamics that have also been observed in relation to NCDs at global level (Heller et al., 2019; WHO, 2018) and which help explain why the emergence of a comprehensive international social movement has been very limited around these diseases. These dynamics are further discussed hereafter.

### ***Patients' associations as pioneers of collective action around diabetes***

By tracing the history of diabetes patients' associations in Mali, this article has highlighted the gap between their early mobilisation and the late uptake by government.

It shows the key role they played in driving collective action and improving access to care, when diabetes was not yet a public health priority. These findings confirm observations made for diabetes (and NCDs) in other countries and at global level. In Africa, the first diabetes association was created in Senegal in 1967 and about 20 countries had already one association member of the International Diabetes Federation prior to 1995 (data collected by the authors from IDF, 2021). Nevertheless, the adoption and the implementation of national policies at country level have remained uneven, in Africa (as shown for Ghana and Cameroon by A. de-Graft Aikins et al., 2010) but also in low-income countries more generally (WHO, 2016). And the management of these diseases in low- and middle-income countries has been largely neglected internationally: the issue of a ‘global diabetes epidemic’ has become visible in international fora only since the late 1990s (Besson et al., 2010), and the UN officially addressed NCDs only 10 years later.

Literature associates this late prioritisation at policy level to different factors: the dependency on international (limited) funding (A. de-Graft Aikins et al., 2010), the framing of several different diseases under a common label (Allen & Feigl, 2017), actors’ little influence on sectors other than health and the late role of guiding institutions and international civil society (Heller et al., 2019). This paper goes more in depth on this last point by analysing what has prevented the emergence of a broad social movement on diabetes (and NCDs) and more specifically what has weakened the pioneering role that some patients’ associations have played. The case of Mali particularly shows that framing processes, resources available, and modes of action performed contributed to limit their ability to have their claims heard and make sustained changes at policy level. These factors are further discussed below.

### ***A fight for medical services more than against broader social inequities***

This paper shows how framing processes and priorities set by patients' associations were not only an eye opener of the specific context of Mali, but they also took social and policy debates in specific directions.

The priority that patients' associations gave to accessibility of diabetes services and treatment brought out the critical need to improve the availability, quality, and affordability of diabetes care within a health system that had long neglected NCDs (Sidibé et al., 2007) and that was challenged by low resources and lack of universal health coverage. Their claims echoed the experience of Malian ordinary patients for whom diabetes was 'the worst disease ever' due to its high costs and to the national and international neglect (Tijou Traoré, 2010). In fact, while no subsidy existed for diabetes treatment during the period of our study, free care policies were largely supported by international donors for HIV/AIDS. These framing processes fit what Brown and Zavestoski (2004) define as a 'health access movement', i.e., one that targets 'equitable access to healthcare and improved provision of healthcare services' (p.685). Yet, the focus on access to care moved public and policy debates towards technical biomedical issues, and obscured the social and psychological impact that diabetes had on patients. De facto, claims made by patients' representatives often silenced the moral suffering experienced by patients as a consequence of their diabetes, for example their partner's departure after they were diagnosed with the disease (Tijou Traoré, 2017).

The other priority given to information and awareness echoed patients' existing frustration for a disease that had long been silenced in public debate, being considered a 'disease of the rich' and due to the lack of epidemiological data (Martini & Fligg, 2011). Yet, this focus on awareness also moved public and policy debates towards preventive issues and behaviour changes at an individual level, with the result that broader

economic and social problems, as well as the need for structural changes, were not even discussed.

These two priorities reveal a collective mobilisation that was only partially connected to patients' experience. This is a crucial difference compared to other health movements that built their collective identity on patients' experience and understanding of their illness from the very beginning of their mobilisation, for example those addressing HIV/AIDS (Epstein, 1996) and cancer (Derbez & Rollin, 2016) in Northern countries. Brown and Zavestoski (2004) define them as 'embodied health movements', since the embodied experience of patients played a central role in framing what they call 'a politicised collective illness identity' (P. Brown et al., 2004, p. 60). Framing processes were *politicised* in that the associations overtly blamed broader social issues; they pointed to structural inequalities and imbalance of power in society as root causes of the diseases.

The tendency to direct public and policy debates towards technical issues and behaviour change is not limited to Mali nor to diabetes. It has been largely observed for NCDs at international level (Clark, 2014; Stuckler & Siegel, 2011; Yang et al., 2018). Yet, it grasps with studies conducted in various contexts and that clearly show social and cultural constraints cause suffering to many diabetes patients (Boivin, 2009; Browne et al., 2013). It also grasps with the large literature existing on the macroeconomic and social structural causes of NCDs (Beaglehole & Yach, 2003; Buse et al., 2017). To conclude this section about framing processes, as Ferguson and colleagues (2016) acknowledged, 'more work has been done to link human rights with communicable diseases' (p.1201), and the potential role that civil society may play in using rights-based approaches has yet to be fully realised for NCDs.

### *Little resources coupled with a fragmented base*

This paper shows that Malian patients' associations lacked resources all over the three stages of their mobilisation. Yet, literature on social movement stress the importance of having sufficient and various resources to engage effectively (Grossman & Saurugger, 2006; Mathieu, 2012; McCarthy & Zald, 1977).

Concerning the mobilisation base and particularly the internal cohesion of the patients' associations studied, the gap found between their representatives and their members converge with what it is found in literature addressing collective mobilisations. In fact, engaging in the public space and participating to policy processes relies upon skills that much depend on socio-economic conditions (Fillieule et al., 2010). Our results, however, contrast about the impact that this gap has. In the literature, the higher socio-economic status of associations' representatives is often considered as a facilitator that gives them access to more effective repertoires of collective action and increases their chance to succeed (Derbez & Rollin, 2016). Conversely, our results raise the question of whether the higher socio-economic status of the associations' representatives has not weakened their capacity to build a collective illness identity. In fact, in the context of a low-income country like Mali where the health system does not ensure quality and affordable care for all, patients experience their illness very differently depending on their status. During the period investigated, better off associations' representatives could often access a broader range of diabetes services, such as expensive treatment and care provided abroad, compared to (often poorer) ordinary members; a situation that has well been assessed in other African contexts (Dimé, 2013).

In addition to this intra-organisational problem, tensions between single associations often gave rise to various separated mobilisations on diabetes rather than to

a whole national mobilisation. This fragmentation at country level is also found at global level where advocacy for specific diseases rather than for NCDs as a whole has been observed for over twenty years (Beaglehole & Yach, 2003; Heller et al., 2019). It should be noted that these tensions are well acknowledged in literature on social movements and are inherent to their network nature (Diani & McAdam, 2003). Recent studies underscored for example the multiplicity of mobilisations on HIV/AIDS in Sub-Saharan Africa (Broqua, 2018). Fragmentation in this area is however linked to a context that is significantly different from that observed in the case of diabetes in Mali : increased funding since the beginning of 2000, an enlarged scope of actions, as well as the quest for autonomy from Northern partners.

Limited external social resources have further reduced the capacity of diabetes associations to build an effective national movement. Social movement theory shows how transnational partnerships provide organisations not only with material and financial resources, but also with knowledge and know-how (della Porta & Tarrow, 2005). Linking to previous movements, to networks of activists and to social relays is also underscored as being key in strengthening the scope and capacities of a social movement (Tilly & Tarrow, 2006). The few external partnerships and the lack of social relays observed around diabetes in Mali, may be linked to a context where low resources and health system dysfunctionalities favour competition for funding rather than collaboration. Still, this might also be linked to the long prevailing view of diabetes as a disease of affluence (Martini et al., 2019b), to the association of the disease with individual misbehaviour, and to the limited references made to human rights. According to Stuckler and Siegel (2011), these cognitive factors have reduced the solidarity towards patients and limited the emergence of a larger collective engagement for NCDs.

Finally, the lack of financial and material resources can be much related to the neglect of diabetes by international donors (Martini et al., 2019b). During the period investigated, Malian patients' associations fighting against AIDS obtained support more easily and did not face the same material and financial constraints (Gobatto et al., 2016). This study also shows the challenges associated with receiving short-term funds, since their impact may not be sustainable. It should be noted that the void left by public (national and international) partners was often filled in by private organisations, including for-profit ones. The latter are currently key in the fight against NCDs at international level (Clark, 2014; Stuckler & Siegel, 2011). This dependency on private actors like pharmaceutical firms or commercial industries raises however the issue of potential conflicts of interests.

### ***Service provision more than militant actions***

In relation with forms of action performed, the priority given by diabetes patients' associations to service provision is in line with current international strategies calling for the involvement of civil society organisations (CSO) in the prevention and control of NCDs (WHO, 2013, 2018, 2019). Yet, while these strategies promote whole-of-society approaches and public-private partnerships, the early mobilisation of diabetes patients' associations filled the voids left by public authorities and mirrored a disillusionment against the State's capacity to intervene for diabetes in Mali. It also reflected the privatisation of public services that international financial institutions have promoted since the 1980 (Roy, 2005), making service provision a main action in the repertoire available to local CSOs.

Forms of actions related to the participation in policy processes highlight the lack of space and voice given to lay knowledge and know-how. As said, the



participation was often delegated to caregivers or the French NGO, and patients' lay expertise was rarely claimed by diabetes associations. A similar trend was observed in relation to the global agenda on NCDs, which has been largely dominated by the professional view of health experts (Clark, 2014). One factor that may explain this passive approach is the fact that sound scientific knowledge on diabetes (and NCDs) has been long established. As Akrich and colleagues show (2009), little room for lay knowledge may remain in such a context. In their study of the rise of international advocacy, Siméant and Taponier (2014) also show that advocacy is a primarily western-centred instrument pushed by donors from late 1990s as the normative character of the ideal civil society. In this light, the few advocacy activities observed in Bamako were undertaken by the municipal associations in the framework of an international funded project; their short course revealed the difficulty of sustained advocacy when it is externally funded and not directly owned by patients' associations.

All in all, the paper shows that overt protest and militant actions were absent from the repertoire of Malian patients' associations. Several factors may explain their softer modes of actions. According to Tilly and Tarrow (2006), forms of engagement strongly depend on the type of regime within which organisations are active. As said above, if violent forms of protest took place in Malian history (Thiriot, 2002), the country has been most known for its weak protest tradition. A study conducted before the military coup in 2012 showed that organised marches were most often peaceful due to either administrative control or institutionalised state-society relationships (Siméant, 2014). Another factor may be linked to the use of modes of actions supported by international donors, notably service provision, but also to a lesser extent advocacy. In this regard, it has been showed that externally funded advocacy often entails more conformist forms of criticism as they are highly standardised by international assistance

(Broqua, 2018; Siméant & Taponier, 2014). Beside these contextual factors, the analysis presented here raises the question of whether the absence of protest may not also be linked to the discipline expected from chronic patients at therapeutic level (Manderson & Smith-Morris, 2010). The interviews revealed a deep concern about patients' adherence to treatment. This goes beyond Mali and treatment only: for example, a statement by the representative of the French Diabetic Association spotlighted the responsibility of this association by linking it to the fact that 'it is not an association of activists' (Raymon, 2013, pp. 227-228). This distinction contrasts with the key role played by activist-oriented organisations in driving important public health changes. To succeed and progressively affect existing balances of power, these organisations overtly challenged medical and scientific paradigms and often worked outside the system to produce knowledge (P. Brown et al., 2004; Landzelius, 2006).

### ***Limitations***

This study focused on diabetes patients' associations active in Bamako. It would be interesting to explore how associations addressed diabetes outside the capital city. Moreover, the period of our study mostly covers the situation of Mali before the military coup in 2012. Since then however, security problems and political instability have greatly disrupted the health system and changed development cooperation into humanitarian aid. This may have had an impact on diabetes associations' frameworks, resources and actions undertaken. Their study may advance the understanding of factors influencing the evolution of the collective mobilisation on diabetes (and NCDs).

## **Conclusion**

The use of a social movement approach to study how diabetes patients' associations engaged in Bamako from 1991 to 2014 has highlighted some of the constraints that weakened their capacity to build a collective national movement able to drive effective policy change over time. In terms of collective action frames, the focus of diabetes patients' associations on technical biomedical issues silenced the daily embodied experience of patients and reduced the use of human-rights approaches. Moreover, few financial, material and social resources coupled with a fragmented base limited the scope and strength of claims made by patients' associations to obtain treatment at reduced costs. Finally, modes of actions performed failed to challenge more structural inequalities and imbalances of power. While partly exacerbated by the context of Mali and particularly by limited political opportunities (Martini et al., 2019a), these constraints reflect some of the current weaknesses of the global mobilisation to address diabetes and NCDs. They should be taken into account when designing and implementing multi-stakeholders' strategies for their prevention and control both at national and global level.

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## References

- Akrich, M., Méadel, C., & Rabeharisoa, V. (2009). *Se mobiliser pour la santé : des associations témoignent [Mobilising for health: associations testify]*. Presses des mines.
- Allen, L. N., & Feigl, A. B. (2017). What's in a name? A call to reframe non-communicable diseases. *The Lancet Global Health*, 5(2), e129-e130.
- Amoah, V. M. K., Anokye, R., Acheampong, E., Dadson, H. R., Osei, M., & Nadutey, A. (2018). The experiences of people with diabetes-related lower limb amputation at the Komfo Anokye Teaching Hospital (KATH) in Ghana. *BMC Research Notes*, 11(1), 66.
- Barbot, J. (2002). *Les malades en mouvements : la médecine et la science à l'épreuve du sida [Patients on the move: medicine and science in the face of AIDS]*. Balland.
- Bazeley, P. (2013). *Qualitative data analysis : practical strategies*. Sage.
- Beaglehole, R., & Yach, D. (2003). Globalisation and the prevention and control of non-communicable disease: the neglected chronic diseases of adults. *The Lancet*, 362(9387), 903-908.
- Benford, R. D. (2013). Frame Disputes. In D. A. Snow, D. della Porta, B. Klandermans, & D. McAdam (Eds.), *The Wiley-Blackwell Encyclopedia of Social and Political Movements*. Wiley Online Library.
- Benford, R. D., & Snow, D. A. (2000). Framing processes and social movements: An overview and assessment. *Annual Review of Sociology*, 26(1), 611-639.
- Beran, D., & Yudkin, J. S. (2010). Looking beyond the issue of access to insulin: what is needed for proper diabetes care in resource poor settings. *Diabetes Research and Clinical Practice*, 88(3), 217-221.
- Besançon, S. (2006). En première ligne : l'Association Malienne de Lutte contre le Diabète [On the frontline: the Malian Association for the fight against Diabetes]. *Diabetes Voice*, 51(3), 38-39.
- Besançon, S. (2009). Les difficultés de la prise en charge du diabète de type 1 [The challenges of managing type 1 diabetes]. *Developpement et Sante*(193).
- Besançon, S., Balcou-Debussche, M., Ferdynus, C., Sidibé, A., & Debussche, X. (2016). Therapeutic education structured by peer educators for type 2 diabetic patients in Mali: Promising results. *Médecine des Maladies Métaboliques*, 10(2), 167-171.
- Besançon, S., Fall, I.-S., Doré, M., Sidibé, A. T., Hagon, O., Chappuis, F., & Beran, D. (2015). Diabetes in an emergency context: the Malian case study. *Confl Health*, 9, 15.
- Besançon, S., & Sidibé, A. T. (2012). Civil society facing down the diabetes emergency in Mali. *Diabetes Voice*, 57(2), 40-42.
- Besançon, S., Sidibé, A. T., Beran, D., & Fleury-Perkins, C. (2018). L'expérience de l'ONG Santé Diabète dans la lutte contre le diabète en Afrique [The experience of the NGO

- Santé Diabète in the fight against diabetes in Africa]. *Médecine et santé tropicales*, 28(4), 363-367.
- Besson, R., Bernard, M., Tijou Traore, A., & Gobatto, I. (2010). Le diabète, une épidémie mondiale? Construction et qualification d'un fait épidémiologique [Diabetes, a global epidemic? Construction and qualification of an epidemiological fact]. In V. Chasles (Ed.), *Santé et mondialisation* (pp. 173-191). Presses Universitaires de Lyon.
- Best, R. K. (2012). Disease Politics and Medical Research Funding. *American Sociological Review*, 77(5), 780-803.
- Boivin, A. (2009). *L'art de la négociation entre son contexte de vie et le diabète de type 2. Stratégies d'autogestion développées par les femmes de l'île de La Réunion [The art of negotiating between one's life context and type 2 diabetes. Self-management strategies developed by women on Reunion Island]*. Université Laval.
- Broqua, C. (Ed.) (2018). *Se mobiliser contre le sida en Afrique : Sous la santé globales, les luttes associatives [Mobilising against AIDS in Africa: Underneath global health, associative struggles]*. L'Harmattan.
- Brown, P., Morello-Frosch, R., & Zavestoski, S. (2011). *Contested illnesses: Citizens, science, and health social movements*. Univ of California Press.
- Brown, P., & Zavestoski, S. (2004). Social movements in health: an introduction. *Sociology of Health and Illness*, 26(6), 679-694.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: new approaches to social movements in health. *Sociology of Health and Illness*, 26(1), 50-80.
- Brown, T. M., & Fee, E. (2014). Social movements in health. *Annual Review of Public Health*, 35, 385-398.
- Browne, J. L., Ventura, A., Mosely, K., & Speight, J. (2013). 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open*, 3(e003384).
- Buse, K., Tanaka, S., & Hawkes, S. (2017). Healthy people and healthy profits? Elaborating a conceptual framework for governing the commercial determinants of non-communicable diseases and identifying options for reducing risk exposure. *Global Health*, 13(1), 34.
- Chaufan, C., & Saliba, D. (2019). The global diabetes epidemic and the nonprofit state corporate complex: Equity implications of discourses, research agendas, and policy recommendations of diabetes nonprofit organizations. *Soc Sci Med*, 223, 77-88.
- Clark, J. (2014). Medicalization of global health 3: the medicalization of the non-communicable diseases agenda. *Glob Health Action*, 7, 24002.
- Crossley, N. (2002). *Making sense of social movements*. Open University Press.
- de-Graft Aikins, A. (2002). Exploring biomedical and ethnomedical representations of diabetes in Ghana and the scope for cross-professional collaboration: A social psychological approach to health policy [Conference Paper]. *Social Science Information*, 41(4), 625-652.
- de-Graft Aikins, A. (2003). Living with diabetes in rural and urban Ghana: A critical social psychological examination of illness action and scope for intervention [Article]. *Journal of Health Psychology*, 8(5), 557-572.

- de-Graft Aikins, A., Anum, A., Agyemang, C., Addo, J., & Ogedegbe, O. (2012). Lay representations of chronic diseases in Ghana: implications for primary prevention [Article]. *Ghana Medical Journal*, 46(2 Suppl), 59-68.
- de-Graft Aikins, A., Awuah, R. B., Pera, T. A., Mendez, M., & Ogedegbe, G. (2015). Explanatory models of diabetes in urban poor communities in Accra, Ghana. *Ethn Health*, 20(4), 391-408.
- de-Graft Aikins, A., Boynton, P., & Atanga, L. L. (2010). Developing effective chronic disease interventions in Africa: insights from Ghana and Cameroon. *Global Health*, 6, 6.
- della Porta, D., & Tarrow, S. (2005). *Transnational protest and global activism*. Rowman & Littlefield Publishers.
- Derbez, B., & Rollin, Z. (2016). *Sociologie du cancer [Sociology of cancer]*. La Découverte.
- Diani, M., & McAdam, D. (Eds.). (2003). *Social movements and networks*. Oxford University Press.
- Dimé, M. (2013). Diabetes of rich, diabetes of poor. Diabetes as an evidence for health inequalities in Senegal. *Comptes Rendues Biologies*, 336(5-6), 249-252.
- Eboko, F., Bourdier, F., & Broqua, C. (2011). *Les Suds face au sida : quand la société civile se mobilise [The South facing AIDS: when civil society mobilises]*. IRD.
- Epstein, S. (1996). *Impure science: AIDS, activism and the politics of knowledge*. University of California Press.
- Ferguson, L., Tarantola, D., Hoffmann, M., & Gruskin, S. (2016). Non-communicable diseases and human rights: Global synergies, gaps and opportunities. *Global Public Health*, 12(10), 1200-1227.
- Fillieule, O., Agrikoliansky, É., & Sommier, I. (Eds.). (2010). *Penser les mouvements sociaux [Thinking about social movements]*. La Découverte.
- Fisch, A., Pichard, E., Prazuck, T., Leblanc, H., Sidibe, Y., & Brucker, G. (1987). Prevalence and risk factors of diabetes mellitus in the rural region of Mali (West Africa): a practical approach. *Diabetologia*, 30(11), 859-862.
- Gobatto, I., & Tijou Traoré, A. (2011). Apprendre à *savoir y faire* avec le diabète au Mali. La fabrique locale des rôles professionnels et profanes [Learning to cope with diabetes in Mali. The local manufacture of professional and lay roles]. *Revue d'anthropologie des connaissances*, 5(3), 509-532.
- Gobatto, I., Tijou Traore, A., & Martini, J. (2016). Rôle du patient et maladie chronique au Mali : entre politiques et pratiques expertes et profanes [The role of the patient and chronic disease in Mali: between policies and expert and lay practices]. *Santé Publique*, 28, 103-111.
- Goffman, E. (1986). *Frame analysis: An essay on the organization of experience*. Northeastern University Press.
- Grossman, E., & Saurugger, S. (2006). Les groupes d'intérêt au secours de la démocratie ? [Interest groups to the rescue of democracy?] *Revue française de science politique*, 56(2), 299-321.
- Hassenteufel, P. (1991). Pratiques représentatives et construction identitaire. Une approche des coordinations [Representational practices and identity constructoin : A study of 'coordinations']. *Revue française de science politique*, 41(1), 5-27.

- Heller, O., Somerville, C., Suggs, L. S., Lachat, S., Piper, J., Aya Pastrana, N., . . . Beran, D. (2019). The process of prioritization of non-communicable diseases in the global health policy arena. *Health Policy and Planning*, 34(5), 370-383.
- Hennink, M. M., Kaiser, B. N., Sekar, S., Griswold, E. P., & Ali, M. K. (2017). How are qualitative methods used in diabetes research? A 30-year systematic review. *Global Public Health*, 12(2), 200-219.
- IDF. (2019). *IDF Diabetes Atlas* (9 ed.). International Diabetes Federation.
- IDF. (2021). *IDF Africa Members*. International Diabetes Federation. <https://idf.org/our-network/regions-members/africa/members.html>
- Imperato, P. J., Handelsman, M. B., Fofana, B., & Sow, O. (1976). The prevalence of diabetes mellitus in three population groups in the Republic of Mali. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 70(2), 155-158.
- Keeling, A. (2011). The UN Summit and beyond: A new era for diabetes. *Diabetes research and clinical practice*, 94, 163-165.
- Landzelius, K. (2006). Introduction: Patient organization movements and new metamorphoses in patienthood. *Social Science and Medicine*, 62(3), 529-537.
- Manderson, L., & Smith-Morris, C. (Eds.). (2010). *Chronic conditions, fluid states. Chronicity and the anthropology of illness* Rutgers University Press.
- Martini, J., & Fligg, A. (2011). L'émergence du diabète de type 2 en tant que problème de santé publique au Mali [The emergence of type 2 diabetes as a public health problem in Mali]. In D. Kerouedan (Ed.), *Santé internationale. Les enjeux de santé au Sud* (pp. 105-119). Presses de Sciences Po.
- Martini, J., Tijou Traoré, A., & Mahieu, C. (2019a). Chronic patient as intermittent partner for policy-makers: the case of patient participation in the fight against diabetes and HIV/AIDS in Mali. *BMC Public Health*, 19(1), 1179.
- Martini, J., Tijou Traoré, A., & Mahieu, C. (2019b). La mise à l'agenda du diabète au Mali : décalage et interdépendance entre acteurs locaux, nationaux et internationaux [Putting diabetes on the agenda in Mali: discrepancies and interdependence between local, national and international actors]. *Politique africaine*, (156), 61-82.
- Mathieu, L. (2012). *L'espace des mouvements sociaux [The space of social movements]*. Éditions du Croquant
- McCarthy, J. D., & Zald, M. N. (1977). Resource mobilization and social movements: A partial theory. *American Journal Of Sociology*, 82(6), 1212-1241.
- MHPH. (2014). *National strategic plan to fight non-communicable diseases 2015-2019*. Ministry of Health and Public Hygiene
- MHPH, MSHAR, & MWCF. (2014). *Health and social development program 2014-2018 (PRODESS III)*. Ministry of Health and Public Hygiene, Ministry of Solidarity Humanitarian Action and Reconciliation, Ministry of Women Children and Families.
- Mshunqane, N., Stewart, A. V., & Rothberg, A. D. (2012). Type 2 diabetes management: Patient knowledge and health care team perceptions, South Africa. *African Journal of Primary Health Care and Family Medicine*, 4(1), 1-7.
- Mwangome, M., Geubbels, E., Klatser, P., & Dieleman, M. (2017). Perceptions on diabetes care provision among health providers in rural Tanzania: a qualitative study. *Health Policy and Planning*, 32(3), 418-429.

- Pichard, E., Berthe, G., Traore, H. A., & Dembele, M. (1988). Les acidocétoses diabétiques au Mali. A propos de vingt cas [Diabetic ketoacidosis in Mali. About twenty cases]. *Annales de la Société Belge de Médecine Tropicale*, 68(1), 67-72.
- Raghavan, N. (1992). Les ONG au Mali. *Politique africaine*(47), 91-100.
- Raymon, G. (2013). Le diabète : une grande cause nationale [Diabetes: a major national cause]. In Collectif (Ed.), *Le diabète. Epidémie silencieuse* (pp. 223-231). Le bord de l'eau.
- Roth, G. A., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., . . . Murray, C. J. L. (2018). Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 392(10159), 1736-1788.
- Roy, A. (2005). La société civile dans le débat politique au Mali [Civil society in the political debate in Mali]. *Cahiers d'études africaines*(2), 573-584.
- Roy, A. (2010). Mali : Instrumentalisation de la société civile. *Alternatives Sud*, 17, 111-118.
- Rutebemberwa, E., Katureebe, S. K., Gitta, S. N., Mwaka, A. D., & Atuyambe, L. (2013). Perceptions of diabetes in rural areas of Eastern Uganda. *Curationis*, 36(1), 1-7.
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., . . . Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893-1907.
- Sidibé, A. T., Besançon, S., & Beran, D. (2007). Le diabète: un nouvel enjeu de santé publique pour les pays en voie de développement: l'exemple du Mali [Diabetes: a new public health challenge for developing countries: the example of Mali]. *Médecine des Maladies Métaboliques*, 1(1), 93-98.
- Sidibé, A. T., Traoré, A., Touré, A., Dembélé, A., Traoré, A., Cissé, I., & Diallo, D. (2000). Suivi ambulatoire du diabétique au Mali [Outpatient follow-up of diabetics in Mali]. *Mali Médical*, 15(3), 41-43.
- Siméant, J. (2014). *Contester au Mali. Formes de la mobilisation et de la critique à Bamako* [Protesting in Mali. Forms of mobilisation and criticism in Bamako]. Karthala.
- Siméant, J., & Taponier, S. (2014). Interpreting the Rise of International "Advocacy". *Humanity: An International Journal of Human Rights, Humanitarianism, and Development*, 5(3), 323-343.
- Snow, D. A., & Benford, R. D. (1988). Ideology, frame resonance, and participant mobilization. In B. Klandermans, H. Kriesi, & S. G. Tarrow (Eds.), *From Structure to Action: Comparing Social Movement Research across Culture* (pp. 197-217). JAI Press.
- Stuckler, D., & Siegel, K. (Eds.). (2011). *Sick societies: responding to the global challenge of chronic disease*. Oxford University Press.
- Tarrow, S. (1993). Cycles of collective action: Between moments of madness and the repertoire of contention. *Social Science History*, 17(2), 281-307.
- Thiriot, C. (2002). Rôle de la société civile dans la transition et la consolidation démocratique en Afrique: éléments de réflexion à partir du cas du Mali [The role of civil society in democratic transition and consolidation in Africa: Some reflections from the case of Mali]. *Revue internationale de politique comparée*, 9(2), 277-295.
- Tijou Traoré, A. (2010). L'expérience dans la production de savoirs profanes sur le diabète chez des patients diabétiques à Bamako (Mali) [Experience in the production of lay knowledge about diabetes among diabetic patients in Bamako (Mali)]. *Sciences sociales et santé*, 28(4), 41-76.



- Tijou Traoré, A. (2017). Souffrance morale, situation de vie et gestion de la maladie chronique chez des patients séropositifs et diabétiques à Bamako (Mali) [Moral suffering, life situation and management of chronic disease in seropositive and diabetic patients in Bamako (Mali)]. In F. Bourdier & C. Grenier-Torres (Eds.), *L'interdisciplinarité. Un enjeu pour le développement* (pp. 159-181). Karthala.
- Tilly, C. (1978). *From mobilization to revolution*. Addison-Wesley.
- Tilly, C. (2004). *Social Movements 1768-2004*. Paradigm Publishers.
- Tilly, C., & Tarrow, S. (2006). *Contentious politics* (Second ed.). Paradigm Publishers.
- UNDP. (2020). *Human development report 2020. The next frontier: Human development and the anthropocene*.
- Vos, T., Lim, S. S., Abbafati, C., Abbas, K. M., Abbasi, M., Abbasifard, M., . . . Murray, C. J. L. (2020). Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet*, 396(10258), 1204-1222.
- WHO. (2013). *Global action plan for the prevention and control of non-communicable diseases 2013-2020*. World Health Organization.
- WHO. (2016). *Global report on diabetes*.
- WHO. (2018). *Final report. WHO GCM/NCD Working Group on the Inclusion of NCDs in other Programmatic Areas (Working Group 3.1, 2016–2017)*.
- WHO. (2019). *Global Dialogue on Partnerships for Sustainable Financing of NCD Prevention Control. Meeting report, Copenhagen, Denmark, 9–11 April 2018*.
- Wing, S. D. (2002). Questioning the state: Constitutionalism and the Malian espace d'interpellation démocratique. *Democratization*, 9(2), 121-147.
- Wing, S. D. (2013). *Démocratie malienne et dialogue constitutionnel (1991-2007): la quête d'un état de droit [Malian democracy and constitutional dialogue (1991-2007): the quest for the rule of law]*. Karthala.
- Yang, J. S., Mamudu, H. M., & John, R. (2018). Incorporating a structural approach to reducing the burden of non-communicable diseases. *Global Health*, 14(1), 66.