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Community Mental Health Journal

ISSN 0010-3853

Community Ment Health J
DOI 10.1007/s10597-017-0192-x



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The Role of Public Health in the Development of a Collaborative Agreement with Rural and Semi-urban Partners in Cases of Severe Domestic Squalor and Hoarding

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Received: 24 November 2016 / Accepted: 4 November 2017
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Abstract When confronted with complex situations of hoarding and severe domestic squalor, small municipal communities and their partners frequently feel overwhelmed due to limited resources at their disposal. Stakeholders often report these situations to Public Health Service and seek their support. In order to facilitate more effective and coordinated actions, the main stakeholders involved (municipal, fire, police, public health and the regional health center) must agree on the most appropriate intervention strategies. An agreement providing services for the management of severe cases of domestic squalor in rural and semi-urban areas located in Quebec, Canada was produced by the Laurentians regional public health, and signed with fourteen local municipalities.

Keywords Collaborative agreement · Public health · Rural · Semi-urban · Severe domestic squalor · Hoarding

Introduction

Health organizations and municipal services in Quebec (Canada) are recurrently facing situations in which individuals hoard either objects or waste, resulting in unsanitary living conditions. Following a complaint or a report, municipal stakeholders such as housing and urban development or fire prevention services are the first to be confronted with this problem. As well, the same reality exists, for health and

social service professionals who provide home-care services. When faced with severe domestic squalor (SDS) or hoarding conditions, these stakeholders often feel overwhelmed and are unable to adequately cope with the problem. In small municipalities where resources are limited this represents a major challenge.

As a result, when the level of domestic squalor reaches a point where it endangers the safety of the occupant and the other inhabitants in the territory of the Laurentian Regional Public Health Service (LRPHS), an intervention might be specifically requested by the stakeholders. The Laurentides is an administrative region of Quebec extending on the north shore of the St. Lawrence River, near Montreal. It is composed 76 municipalities with a population of more than half a million people on 20,560 km². These complex situations often require different levels of intervention in order to deal with the individual and the unsanitary conditions. This makes collaboration between the stakeholders the avenue of choice (Frank and Misiaszek 2012; Snowdon and Halliday 2009; Snowdon et al. 2012). This paper presents a descriptive study of the process leading to a collaborative municipal inter-agency agreement (MIAA) used by several municipalities in the Laurentian region and, as well, outlines the role of the LRPHS.

What is Severe Domestic Squalor?

According to Snowdon et al. (2012), severe domestic squalor is not a medical diagnosis but a report on living conditions. In fact, SDS is the result of behavior that can be attributed to several different causes and is often associated with various medical conditions or diagnoses such as dementia, alcoholism and schizophrenia (Snowdon and Halliday 2009). Since 2015, The DSM-V has recognized that SDS can also be the result of an anxiety disorder characterized by compulsive

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hoarding; otherwise described as a persistent difficulty in throwing away or disposing of objects, goods and/or belongings no longer considered useful. This behavior results in an accumulation of objects that occupies what would normally be living areas and, thereby, disrupt the primary function of these spaces (The American Psychiatric Association 2013; Mataix-Cols et al. 2010). Others may use diagnostic terms such as Sylllogomania or the Diogenes syndrome to describe individuals in situations of SDS; the latter syndrome referring to a personality disorder often associated with aging, self-neglect and the lack of proper hygiene (Monfort et al. 2010). (Table 1). All these terms recognizes the development of significant excessive, obsessive and compulsive behavior. For the sake of this article, we define SDS as the effect of a behavioral problem with or without any known associated psychiatric diagnosis.

The prevalence of SDS is largely unknown and is often underestimated. Different studies have varying classification criteria making them difficult to compare. However, in general, it is estimated that compulsive hoarding behavior affects 1–2% of the population—principally the elderly who live alone and are socially isolated (Snowdon et al. 2012). The support normally provided by municipal and medical services is considered problematic due to both the lack of cooperation between the different stakeholders and by the reluctance of some patients to cooperate. The interventions also raise certain ethical issues, namely, the boundary between the respect for individual freedoms and the possible lack of assistance to a person in danger (South Australia Department for Health and Ageing 2013).

The Effects of Severe Domestic Squalor on Health

SDS can become a major health risk. The nature of the risk can be chemical, physical, biological, or even psychological in origin. The severe unsanitary conditions may also constitute a risk to various stakeholders such as: nurses for Local

Health and Social Service Centre (CLSC), inspectors, fire-fighters, police, paramedics, cleaning and decontamination specialists, landlords, volunteers, etc.

The lack of hygiene, the accumulation of waste, leftover food and paper, the large number of animals and their droppings, encourage the presence of biological contaminants (mold, bacteria, and insects) that can cause allergies, asthma, gastro-enteritis, pulmonary irritation, recurring infections, dermatitis, flea and bedbug infestations or the worsening of already existing diseases. In addition, the accumulation of various chemicals, including certain incompatible substances, can cause respiratory tract irritation, nausea, headaches, severe burns and loss of life due to an increase risk of fire.

Methods

The Need for an Agreement

In order to coordinate a more effective intervention, the main partners' involved (municipal authorities, fire prevention, police, the LRPHS and the regional health network) must agree on the specifics of a coordinated effort. The development of a MIAA allows for improved collaboration and, ultimately, the improvement of services rendered to individuals living with SDS.

Ideally, and whenever possible, the main objective of any intervention is to provide the help an individual needs in order to remain living at home. The intervention is also an opportunity to provide a privileged contact with the CLSC. This desired approach is well described in the literature and has been applied in several major cities around the world (Catholic Community Services 2014; Agence régionale de santé Rhône-Alpes 2012; Seniors association of greater Edmonton 2013; Metropolitan Boston housing partnership 2015; Metropolitan Washington Council of Governments

Table 1 Definitions

Squalor^a

Squalor describes an unsanitary living environment that has arisen from extreme and prolonged neglect, and poses substantial health and safety risks to people or animals residing in the affected premises, as well as others in the community

Hoarding^a

Hoarding behaviour is the persistent accumulation of, and lack of ability to relinquish, large numbers of objects or living animals, resulting in extreme clutter in or around premises

This behaviour compromises the intended use of premises and threatens the health and safety of people concerned, animals and neighbour
DSM-V Hoarding Disorder

Diogenes syndrome^b

Diogenes syndrome (DS) is a behavioural disorder characterized by domestic filth, or squalor, extreme self-neglect, hoarding, and lack of shame regarding one's living condition. It is often associated with other mental illnesses, such as schizophrenia, mania, and fronto-temporal dementia

^aPavlou and Harris (2016)

^bIrvine and Nwachukwu (2014)

2006; South Australia Department for Health and Ageing 2013).

Description of the Agreement

Context

The LRPHS covers a large semi-urban and rural region of approximately 600,000 inhabitants, divided into 76 municipalities, north of Montreal, in Quebec, Canada.

In 2009, just as the LRPHS had begun reflecting on the types of possible interventions in cases of SDS, one of the regions municipalities contacted the LRPHS in order to establish a partnership. The nature and complexity of their problems cannot be solved by a single stakeholder. Many have multiple problems such as mental and physical illness, relationship issues, substance abuse, poverty, and illiteracy. So assistance from various sources is needed an, a coordinated approach is necessary. Inspired by an agreement created by our colleagues from the Quebec Regional Public Health Service and our Ontario colleagues (Pelletier and Pollett 2000), we adapted their model to reflect the reality and specificity of the Laurentians region. The MIAA was analyzed by a lawyer for any legal ramifications. We tested this agreement for a 3 years period with the municipality in question and the CLSC serving the community. The CLSC provides frontline common health and social services, as well as preventive, curative, rehabilitative and reintegration services. The CLSC must ensure that any persons needing such services are contacted, that their needs are evaluated and the required services are provided whether it's at home, at school, or at work.

Since then, 14 other municipalities, ranging in size from 1800 to 67,300 inhabitants, have signed the agreement with their local partners. (Table 2) The principal stakeholders involved are the main signatories of the MIAA. These signatories are the municipalities (via their housing and urban development, fire, and police services), CLSC's, and the LRPHS. In one case, the municipal housing office also signed the agreement.

Depending on the particular situation, other non-signing partners may be called upon to support the intervention. These partners, having various expertise's, are able to provide necessary additional resources when needed. For example, when in the presence of children, the Youth Protection Agency (*Direction de la protection de la Jeunesse (DPJ)*) is called. When animals are involved, the Ministry of Food, Agriculture and Fisheries (*Ministère de l'Agriculture, des Pêcheries et de l'Alimentation du Québec (MAPAQ)*) may be called, etc. All other community groups present on the territory in question may also be called upon to contribute according to need and the services they can provide.

Disclosure

Family or neighbors often report situations of SDS directly to the municipality or to the LRPHS. In fact, any witness of this condition can also report the situation to a signing member of the MIAA. Some signatories may also, in the context of their work, discover a problematic situation. This is frequently the case for fire prevention services as a result of their prevention and in-home support services mandate.

Assessment

Each partner is able to conduct a baseline assessment of the two components of the MIAA; the individual and the dwelling. If the person is considered to be in medical danger (psychiatric decompensation), a voluntary or imposed referral for an in-hospital assessment will be made. If there is any doubt as to the security of the dwelling, either in terms of its infrastructure or the possibility of a fire hazard, a request will be sent to the municipalities' urbanism or fire services. If children are present and are considered to be at risk, a reference will be sent to the Youth Protection Agency.

In the majority of cases, the individuals concerned do not ask for help themselves and are often reluctant at first. In our experience, however, more than 80% of these individuals we meet in cases of SDS eventually collaborate. The reluctance to cooperate by these individuals is a similar response seen with homeless individuals and drug addicts

Table 2 Number and prevalence of SDS cases encountered per year for each Local Health and Social Service Centre

Health centre	Number of cases per year			Population 2014 ^a	Incidence 2014–2015/10,000 pop
	2012–2013	2013–2014	2014–2015		
1		5	13	35,273	3.7
2		8	9	42,018	2.1
3		12	23	155,539	1.5
4		5	7	46,182	1.5
5	11	24	25	159,004	1.6
Total	11	54	77	438,016	1.8

^aSource: ISQ, 2011–2036 projections (Nov 2014)

during interventions. This suggests that a similar approach could also be relevant (Tompkins 2011).

Despite an assessment which may consider these persons able to make their own decisions, they nonetheless have a high risk profile. This high risk profile can include self-neglect, injuries due to a risk of falling, nutritional problems and an extreme lack of proper hygiene, accompanied or not, by a risk of infection. These situations may also represent for neighbors and social workers fire safety risks

and environmental health issues. As a result, and depending on the individuals' cooperation, a contingency plan will be implemented (Fig. 1).

Intervention

In cases of SDS, the dwellings are often considered unsafe; emphasis is placed firstly on decluttering the dwelling for security reasons rather than on the reasons that led to

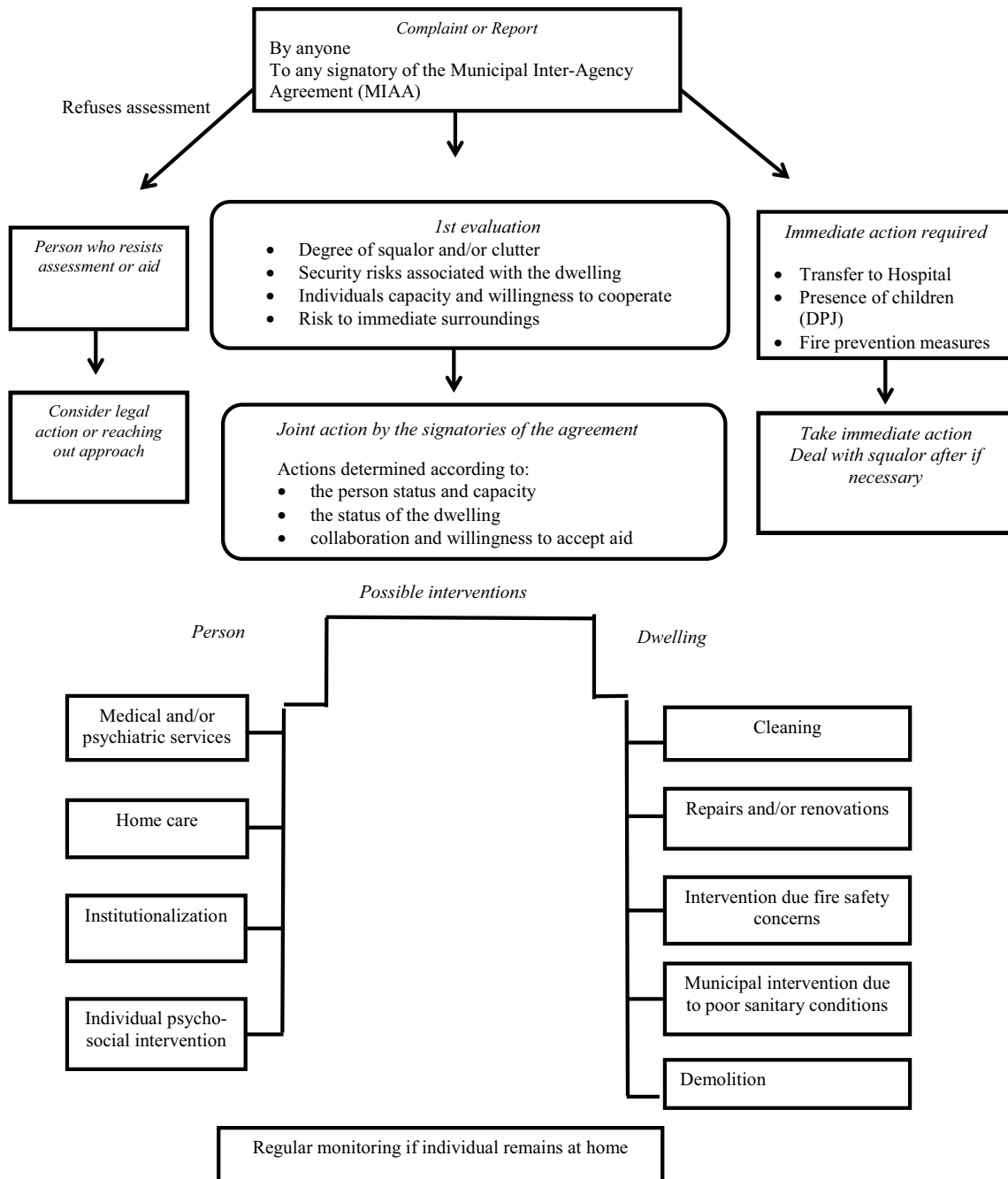


Fig. 1 Severe domestic squalor (SDS) intervention algorithm

hoarding in the first place. Therefore, an intervention is normally performed in two stages. Firstly, a harm reduction cognitive-behavioral approach is attempted to at least minimally de-clutter the dwelling. The situations degree of urgency will modulate the degree of intervention used (Tompkins 2011; Chateret al. 2013). Secondly, a request for assistance is immediately made to the Local Health Centre's psychosocial services.

As a result of municipal regulations in effect, the municipality's fire department or urbanism services might be required to emit a notice of infraction concerning the safety or the maintenance of the building. These notices will often serve as motivators toward change for the person involved. Furthermore, they also provide opportunities for the social service to get involve in cases by offering help. However, flexibility in the application of these offences and their penalties is essential to allow the person time to take charge of oneself.

In cases of SDS, individuals often perceive the arrival of social services, health care or other workers as an intrusion. This makes the success of an intervention very fragile. Failure could lead to further withdrawal and to an increase in their vulnerability (Amanullah et al. 2009). Therefore, an appropriate approach to the problem using small steps and small and achievable goals is preferable and might have more success than a radical type intervention. The establishment of trust with psychosocial workers is essential for these people and helps break their isolation. After trust has been established, the objective of clearing and cleaning the dwelling should first be approached according to security guidelines followed by health considerations. In this context, one will focus primarily on decluttering exits rather than clearing the kitchen counters. A more conventional approach to cognitive-behavioral therapy can then be undertaken in accordance with the medical and psychiatric diagnosis.

Each case must be viewed holistically and adapted to the personality of the individual, the severity of the case, their entourage and their environment. For example, a mother with children, living in an apartment with more than 20 cats will be handled differently than a 50 years old man living alone and who collects newspapers in his home. Each case is different and, therefore, no single generalized strategy is applicable. An appropriate individualized plan of action must be developed with the relevant partners who work within their usual and specific intervention framework. In fact, the MIAA specifically outlines and establishes the legal framework for each partners' intervention (Fig. 2).

Health and Safety of Stakeholders

While establishing a relationship based on trust with the person visited, the health and safety of stakeholders making on-site interventions must be protected. A guide for this

purpose was developed by the LRPHS and presents the main health risks encountered in cases of SDS (ASSTSAS/Agence de santé et services sociaux des Laurentides, Direction de santé publique 2012).

Special Law for the Protection of Personal Information

In Quebec, health services are subject to a special personal information protection law. Those rights are governed by the Québec Civil Code, specifically, the Act respecting Access to documents held by public bodies and the Protection of personal information and the Act respecting the protection of personal information in the private sector. This law enables clinical teams to discuss and share patient information among them but excludes all other stakeholders not considered as being part of the healthcare team (city, firefighters, police, etc.). As a result, the patients consent must be obtained before transmitting any healthcare related information to these 'non-healthcare' stakeholders. Although rarely acquired at the beginning of an intervention, in the majority of cases stakeholders are able to acquire the persons consent. This, however, causes a delay in the implementation of any support measures.

Results and Discussion

So far, over 14 municipalities—which represent almost half of the Laurentian territory's population—have signed the MIAA. As well, five CLSC's are signatories and serve more than 75% of the region's population. The number of interventions is highly variable depending on the underlying problems identified. One or two meetings may be sufficient for emergency referrals and/or transfers. However, other cases of SDS may require multiple interventions, particularly if several different health care professionals are involved. By 2015, the average number of visits required was 9.3 visits per person per year. Of the 110 people encountered, we were provided with only a minimum of information. But we were able to determine that the average age of the individuals in cases of SDS in the region is 59 years old and that the sex ratio is 53 men and 57 women.

In accordance with the activities outlined in the Ottawa Charter, the LRPHS acts in the area of health promotion by introducing the idea of healthy housing within municipalities (World Health Organisation 1986). It also acts as a mediator (Table 3) and acts to empower partner and stakeholder interventions. However, despite the fact that SDS is considered to be an individual health problem and normally outside the purview of the LRPHS, the management of SDS cases in rural and semi-urban areas often requires more direct support on the part of the LRPHS to act as a scientific expert and facilitator. The need for a more direct intervention can

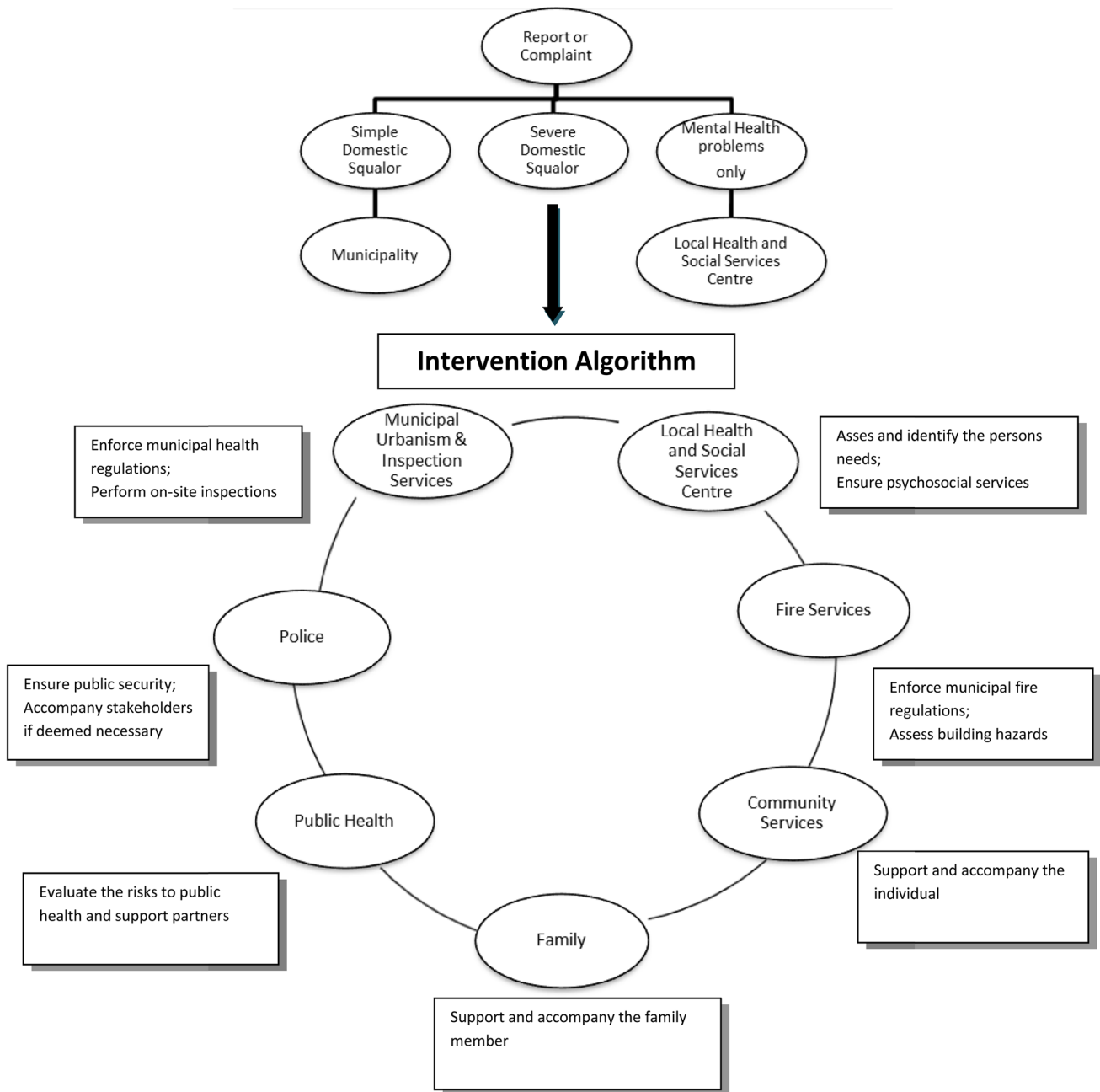


Fig. 2 Role of stakeholders in cases of severe domestic squalor (SDS)

possibly be explained by the fact that experienced resources are often limited in small municipalities. Indeed, the presence of part-time firefighters, limited resources in the urbanism departments and the small number of cases occurring annually would make these stakeholders less skilled in handling these types of situations.

The advantages of this approach is a more personalized and coordinated case management which takes into account the individuals environment and entourage and also decreases the risks associated with a cluttered

dwelling. As well, it allows the intervention team to cope with varying degrees of health risks associated with various medical problems. The main difficulties encountered are: the sharing of confidential medical information, staff mobility, and the reconciling of different organizational cultures.

As the LRPHS becomes a necessary stakeholder for smaller municipalities and the Local Health and Social Service Centre's, one should see a reduction in the municipalities associated costs (McDermott and Gleeson 2009).

Table 3 Role of Laurentians regional public health services

Role of Laurentians regional public health services
Educate key municipal leaders and health community managers
Bring together the stakeholders potentially involved in the interventions
Establish a work group
Clarify the type of intervention and the role of each partner
Serve as a scientific expert in cases of SDS
Establish an epidemiological monitoring mechanism
Develop guidelines for the protection of workers and stakeholders against infectious, chemical, physical and psychological risks
Develop or translate the intervention tools required

Conclusion

This article presents an intervention algorithm for cases of SDS occurring in small municipalities and also defines the role of the LRPHS. Further epidemiological studies would be required to better understand the affected individual and the problem of SDS in general. Also, it would be interesting to reflect on early recognition and prevention mechanisms related to this problem, especially in a society where life expectancy is increasing.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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