Implementation and evaluation of health passport communication tools in emergency departments

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ABSTRACT

Background: People with IDD (intellectual or developmental disabilities) and their families consistently report dissatisfaction with their emergency department experience. Clear care plans and communication tools may not only improve the quality of patient care, but also can prevent unnecessary visits and reduce the likelihood of return visits.

Aims: To evaluate communication tools to be used by people with IDD in psychiatric and general emergency departments in three different regions of Ontario.

Methods and procedures: Health passport communication tools were locally tailored and implemented in each of the three regions. A total of 28 questionnaires and 18 interviews with stakeholders (e.g., hospital staff, community agency representatives, families) were completed across the regions to obtain feedback on the implementation of health passports with people with IDD.

Outcomes and results: Participants felt that the health passport tools provided helpful information, improved communication between patients with IDD and hospital staff, and were user friendly. Continued efforts are needed to work with communities on maintenance of this tool, ensuring all hospital staff are utilizing the information.

Conclusions and implications: These findings emphasize the merits of health passport tools being implemented in the health system to support communication between patients with IDD and health care practitioners and the importance of tailoring tools to local settings.

What this paper adds?

This paper makes a contribution towards better understanding the utility of communication tools in Emergency Departments for patients with IDD and their impact on patient-health care provider communication. This paper was strengthened by including 3 implementation sites and obtaining feedback on this tool from various stakeholders, and by combining survey and interview data.

1. Introduction

Individuals with IDD (intellectual or developmental disability) are more likely to visit emergency departments and be hospitalized than individuals without IDD. Repeat emergency visits and rehospitalizations are also more common for these individuals (Lunsky & Balogh, 2010; Lunsky et al., 2012). There is strong agreement that visits to emergency departments by those with IDD are extremely stressful for them (Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014), their caregivers (Weiss, Lunsky, & Gracey, 2009) and hospital staff (Iacono et al., 2014). One contributor to the stress is the poor communication between patients and health care practitioners.
A significant barrier to care of individuals with IDD is information gaps encountered by health care professionals (Lunsky, Gracey, & Gelfand, 2008; Lunsky et al., 2014). Hospitals feel ill equipped to care for their patients with IDD because information is either not there, or the format of the information is too cumbersome for a rapid paced environment. Many hospital staff indicate that serving individuals with IDD requires significant effort and is not only time consuming but extremely difficult because they are typically provided with very little background information. Hospital staff also often have trouble communicating effectively and efficiently with other service providers and caregivers (Lunsky et al., 2008; Sowney & Barr, 2007). Not surprisingly, people with IDD (Lunsky & Gracey, 2009) and their caregivers (Weiss et al., 2009) report dissatisfaction with their emergency department experience. Vehicles to improve patient-provider information are crucial in this regard. Clear care plans and communication tools may not only improve the quality of patient care, but they can also prevent unnecessary visits, reduce the likelihood of return visits, and relieve health care professionals’ stress and emotional exhaustion.

1.1. Communication challenges in the emergency department

While primary care providers have the opportunity and objective of consistent and comprehensive communication with patients with IDD (Sullivan et al., 2011), hospital staff have fewer opportunities for these comprehensive communications with patients as there is insufficient time to support this flow of information. In an emergency situation, hospitals require key information quickly about diagnosis, medications, allergies, history of the problem, and supports available to keep patient and staff safe, to drive decision making, and to improve patient comfort.

It can be very difficult for individuals with IDD, particularly when under stress, to provide such information (Sharby, Martire, & Iversen, 2015). They have communication barriers (Cook & Lennox, 2000), memory impairments (Henry, 2010; Henry & Gudjonsson, 2007), and are more likely to acquiesce or offer information they believe the authority figure wants to hear (Perske, 2010, 2011), than other less vulnerable groups. Moreover, these individuals may have idiosyncratic ways of communicating that may not be readily understood by those who do not know them (Chew, Iacono, & Tracy, 2009). As such, people with IDD may often have trouble communicating what their issues are and in providing accurate historical information (see Lunsky et al., 2014 for review).

Further challenges are encountered by staff in Emergency Department (ED); nurses find it challenging to communicate with patients with IDD (Sowney & Barr, 2007). In fact, across disciplines hospital staff report that they feel unprepared to respond to the IDD population (Lunsky et al., 2008). Nurses in the ED consistently describe communicating with patients with IDD as challenging; they find it difficult to obtain consent and generally lack knowledge of the IDD population (Sowney & Barr, 2007). As such, when communicating with patients with IDD, the staff may use difficult, ambiguous or inappropriate words, or provide confusing or overly complicated explanations (Lunsky et al., 2014).

1.2. Health passports

Health passports are designed primarily to be read by healthcare professionals who work in hospitals and clinics. Though typically brief, they provide substantial information about the individual, such as their photograph (useful to see how the person looks when well and healthy), their likes and dislikes, how the individual communicates (e.g., verbal/non-verbal, communication device use), medical history, current medication, supports needed with respect to eating and drinking, and how the individual copes with medical procedures. Health passports are designed to be evolving documents that can be easily modified and updated. These brief documents help to promote a consistent approach for these individuals, who are likely to need treatment from a range of healthcare providers.

Health passports for individuals with IDD to be used in hospitals were first introduced in the UK in 1990. In 2011, a UK health passport was modified for use in the US through University of South Florida, with growing appreciation for this tool there. Despite the increasing popularity of health passports generally, surprisingly little research has evaluated their utility, from either the health care provider or patient perspective. In our comprehensive review of the literature, we found only 3 studies specifically focused on health passports, each descriptive in nature.

1.3. What is known about the impact of health passports

Brodrick et al. (2011) described and informally evaluated the development of a one-page patient health passport for people with IDD in UK. The process for developing this patient health passport followed several steps. First, a working group of several community organizations met with hospital to identify information required at the ED from presenting patients. Reviewed literature and existing health passport examples yielded a selection of one health passport as a template. This health passport was modified into a briefer tool for their purposes and was then distributed to approximately 150 patients and families. Based on group discussions held by working group members and staff involved in this pilot project, there was user reported satisfaction with the health passport. Discussions specifically highlighted the user-friendly features of the health passport (e.g., easily recognizable, saves time on admission, and simple to store and update). Moreover, the informal feedback received from services that had used the health passports relayed that the patient health passports helped improve the hospital stay of people with IDD. However, an important challenge in utilizing the health passport was identified; not all staff (particularly in emergency department) were aware of patient health passports. This lack of communication hindered the use of health passports and was highlighted in the study as an important area for improvement. The authors attributed success of their health passport implementation to: its simple design, coordinated approach...
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