A positive risk approach when clients choose to live at risk: a palliative case discussion

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Purpose of review
The article discusses recent approaches in the literature about clients who chose to live at risk in their homes. It argues for a positive risk-based approach and a tool to help manage risk in the home, and applies these to a hypothetical end-of-life scenario.

Recent findings
Historically, safety plans to consider risk management involved a culture of risk aversion supported by sometimes paternalistic motives intended to protect vulnerable clients. New findings in the literature engage in a process that respects the ethical principles underlying harm reduction philosophies. The literature also argues for a perspective that moves away from viewing risk as only harmful, to one that supports a positive understanding of risk as part of a client's informed choice.

Summary
A risk support management plan, based on a positive approach, can provide a way to both support a client's choice to live at risk, anticipate for expected complications, and inform the creation of a contingency plan to address concerns as they may arise. The added value of a structured approach like the one proposed here for risk support management plans is that it provides adequate due diligence and informed decision-making when planning for risk-taking in complex situations.

Keywords
dying at home, end-of-life, ethics, home care, palliative care, positive risk, risk

INTRODUCTION

Home care is the most rapidly growing segment of the Canadian healthcare system [1]. In 2011, Canada had a population of just over 34 million [2]. In that same period, 1.4 million Canadians received home care, representing a 55% increase in clients from 2008 [3]. Reasons for this increase in home care usage have been attributed to an aging population, overcrowding in acute care hospitals, shortages of long-term care beds, and increased rates of disability and chronic illness across the country [3].

The reality that people are living longer with chronic life-threatening illnesses has meant an accumulative increase in demand for care in the home. In Canada, the underlying cause of most deaths is attributed to advanced chronic illness [4]. Individuals living with an advanced illness choose to spend the majority of their last months of life being cared for at home, regardless of the ultimate location of death [5].

With homecare poised to continue to grow, both in Canada and internationally [6], the mandate to understand and effectively manage risk (safety) in the home setting is receiving priority [7▪]. A significant gap in risk management is the absence of 'structured mechanisms' and tools to support safety for clients and care providers in the home [7▪]. In society, individuals are generally free to make their own decisions regarding the level of risks they are willing to undertake for themselves. However, when care is being negotiated in the home setting, it can be expected that the healthcare teams and their clients may not share the same priorities or even assessment of risks. Clients will have differing values

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KEY POINTS

- Increasing demand on home care will involve more service providers working in unsupervised and risk-prone environments.
- Emphasis toward 'client-centered care' involves reasonable and easy-to-use structured mechanisms to support capable clients choosing to live at risk.
- Service agencies and staff need tools that respect harm reduction philosophies as well as a positive approach to risk to facilitate a mutually safe environment for care to be provided.

and opinions – and in a society that values autonomy – the question remains: Should a capable client be allowed to engage in risks that can impact the welfare of others involved in supporting them [5]? A unique and important feature of the services being provided in a home care setting rests on the realization that all safety concerns of the client are closely intertwined with those of the family and the care providers that surround them [8,9].

In this article, we begin by exploring the traditional risk management strategies that placed emphasis primarily on risk avoidance and aversion. We argue that this protective and sometimes paternalistic concept of risk needs to change: from one that speaks only to working against risk (attempts at its mitigation and/or elimination) so as to avoid harms, to one that focuses on risk also having potentially beneficial or positive outcomes [10]. Our argument will be advanced using a new positive risk support management tool, applied to a hypothetical home palliative care case where a client chooses to live at risk. This case will illustrate how adopting a new ethical lens can enable the negotiations between clients and their care providers to push risk beyond an autonomy versus harm calculus, to one that includes reasonable accommodation for positive risks to be supported.

ETHICAL ISSUES OF RISK MANAGEMENT IN THE HOME: AN EVOLVING LANDSCAPE

Strategies to assess and manage risk in healthcare have seen significant evolution over time. Historically, risk has been perceived negatively and referenced using terms, such as danger, loss, threat, damage, and injury [11,12▪▪]. This risk aversion approach prioritized the ethical principle of doing no harm (nonmaleficence) over one that supported or legitimized the principle of individual autonomy. In many institutions and assisted living centers, risk aversion approaches resulted in restrictive policies and practices being implemented – many of which were also used for care in the home. The disability rights movement has outlined how these historically negative and preventive approaches to risk were disproportionally restrictive, even paternalistic, further marginalizing people with disabilities. In the case of capable persons living with disabilities, even if understood to be well intentioned to prevent harm, these restrictive approaches sometimes removed the right to capable self-determination and autonomy [8,11].

More recently, research has shown that clients' choosing to live with risk can in fact be instrumental in the way they manage their health and its effects on their lives [10]. For some, risk-taking can be viewed as a positive choice, permitting healthcare clients to have greater choice and control of their lives; in some cases, it can be their preferred way to discover new personal strengths and capabilities [11,12▪▪].

Research in the area of harm reduction theory, has shown that some chosen risk behaviors are paradoxically a matter of survival for some clients, suggesting that these behaviors can in fact be proportionally or functionally beneficial for that individual [10]. This insight is frequently viewed as counterintuitive to some healthcare professionals not trained in this approach. In that, what might readily be recognized as harmful or even irrational behavior (i.e., excessive drinking, recreational and illicit drug use), may actually be the only available strategy a client can use to mitigate a more painful harm in their life (i.e., trauma, loss, psychic pain) [13]. Unfortunately, a restrictive and risk-averse approach frequently overlooks or dismisses this reality.

TOWARD A NEW POSITIVE APPROACH TO RISK

A positive risk-taking approach considers risk as having two potential outcomes: one that may provide direct benefit to the client, and the other that may have harmful outcomes to the client and/or others with whom they come into contact [10]. A positive approach to risk aims to balance this twofold approach when cocreating a risk support management plan with the client, family, and service providers. The goal is to build a plan that both supports and recognizes the desired benefits identified as meaningful by the client, while working to minimize the negative consequences where possible [11].

Ethically, a positive risk-taking approach respects individual autonomy. It does this by engaging a capable client's desire to live at risk as being

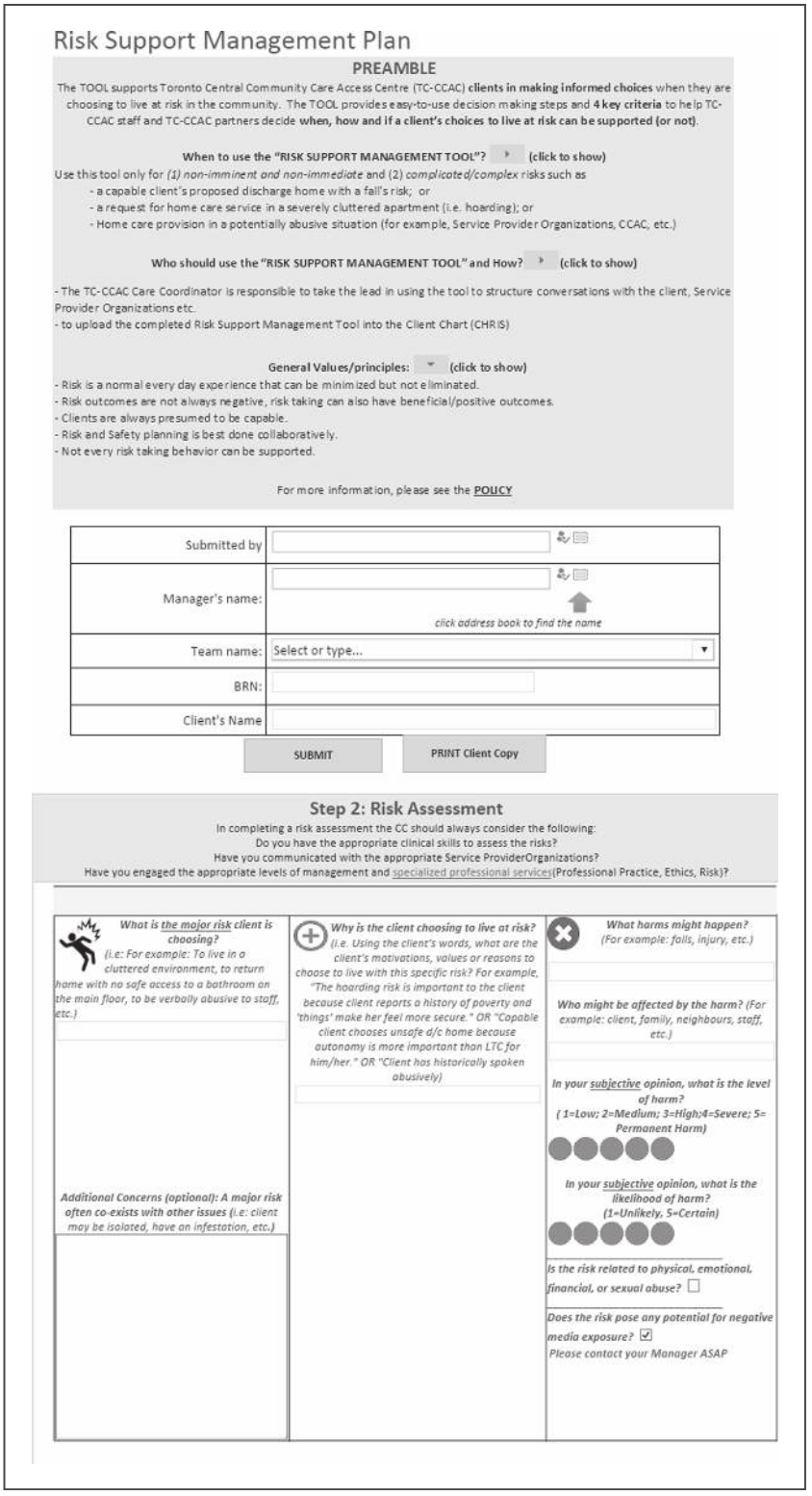
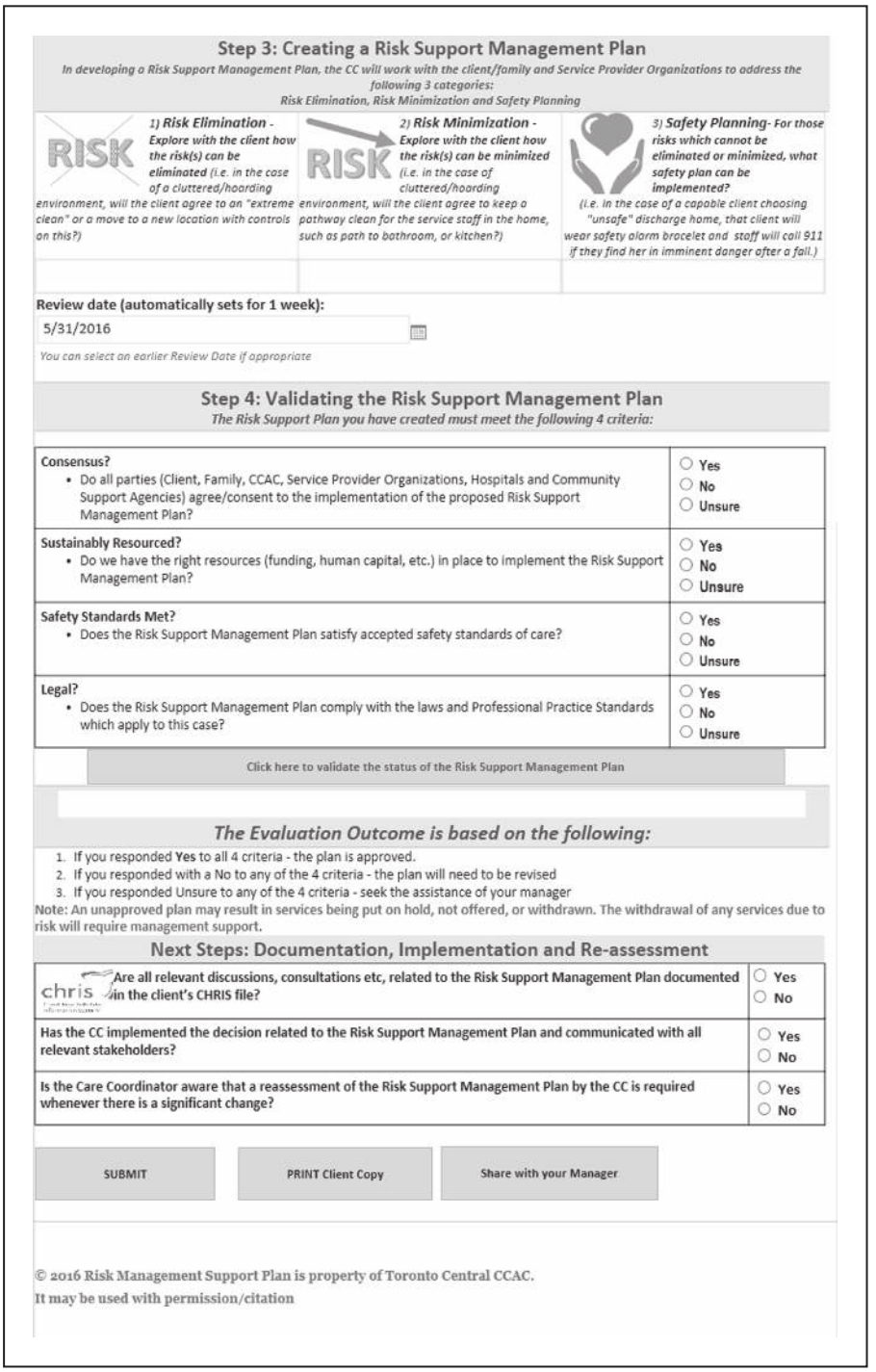


FIGURE 1. The figure presents a new 'risk support management plan' developed by the TC-CCAC. It is designed to support clients/patients in making informed choices when they are choosing to live at risk in the community. The tool provides easy-to-use decision-making steps and four key criteria to help TC-CCAC staff and TC-CCAC partners decide when, how, and if a client's choices to live at risk can be supported (or not). Note, this tool is presented with permission from the TC-CCAC. TC-CCAC, Toronto Central Community Care Access Centre.



Step 3: Creating a Risk Support Management Plan

In developing a Risk Support Management Plan, the CC will work with the client/family and Service Provider Organizations to address the following 3 categories:
Risk Elimination, Risk Minimization and Safety Planning

*1) **Risk Elimination** - Explore with the client how the risk(s) can be **eliminated** (i.e. in the case of a cluttered/hoarding environment, will the client agree to an "extreme clean" or a move to a new location with controls on this?)*	*2) **Risk Minimization** - Explore with the client how the risk(s) can be minimized (i.e. in the case of cluttered/hoarding environment, will the client agree to keep a pathway clean for the service staff in the home, such as path to bathroom, or kitchen?)*	*3) **Safety Planning**- For those risks which cannot be eliminated or minimized, what safety plan can be implemented? (i.e. in the case of a capable client choosing "unsafe" discharge home, that client will wear safety alarm bracelet and staff will call 911 if they find her in imminent danger after a fall.)*

Review date (automatically sets for 1 week):

5/31/2016

You can select an earlier Review Date if appropriate

Step 4: Validating the Risk Support Management Plan

The Risk Support Plan you have created must meet the following 4 criteria:

Consensus? • Do all parties (Client, Family, CCAC, Service Provider Organizations, Hospitals and Community Support Agencies) agree/consent to the implementation of the proposed Risk Support Management Plan?	○ Yes ○ No ○ Unsure
Sustainably Resourced? • Do we have the right resources (funding, human capital, etc.) in place to implement the Risk Support Management Plan?	○ Yes ○ No ○ Unsure
Safety Standards Met? • Does the Risk Support Management Plan satisfy accepted safety standards of care?	○ Yes ○ No ○ Unsure
Legal? • Does the Risk Support Management Plan comply with the laws and Professional Practice Standards which apply to this case?	○ Yes ○ No ○ Unsure

Click here to validate the status of the Risk Support Management Plan

The Evaluation Outcome is based on the following:

1. If you responded **Yes** to all 4 criteria - the plan is approved.
2. If you responded with a No to any of the 4 criteria - the plan will need to be revised
3. If you responded Unsure to any of the 4 criteria - seek the assistance of your manager

Note: An unapproved plan may result in services being put on hold, not offered, or withdrawn. The withdrawal of any services due to risk will require management support.

Next Steps: Documentation, Implementation and Re-assessment

chris **Are all relevant discussions, consultations etc, related to the Risk Support Management Plan documented in the client's CHRIS file?**	○ Yes ○ No
Has the CC implemented the decision related to the Risk Support Management Plan and communicated with all relevant stakeholders?	○ Yes ○ No
Is the Care Coordinator aware that a reassessment of the Risk Support Management Plan by the CC is required whenever there is a significant change?	○ Yes ○ No

SUBMIT | PRINT Client Copy | Share with your Manager

(continued)

motivated by a hoped-for outcome that is important and meaningful to the client. This aspect of hearing what is most important to clients is at the core of the risk support management tool developed by the Toronto Central Community Care Access Centre, and presented in Fig. 1. The tool builds on and adapts other best practices [11] and offers a structured way to engage these conversations, beginning with a risk assessment approach that seeks to understand what is most important to the client as well as risk management, and key validation criteria to check if the proposed plan is viable.

A hypothetical end-of-life home care case is used (inserted in italics in four parts) to illustrate a positive risk assessment approach. In the case described, we hear what might appear to be a perplexing reason for this client's choice to stay at home with the risk of self-reported abuse: 'If I leave, my wife will 'win' and will control everything.' Initially, the team found this reasoning hard to understand and support; however, further prompting enabled the team to 'buy-in' to the client's goal.

The case: part 1: identifying the major risk and why the client is choosing it

Mr. M is 55 years old with metastatic prostate cancer. Discharged from hospital for palliative care, he lives with his wife who is also his primary caregiver. They have a long history of mutual, physical, and emotional abuse.

His home care nurse feels that Mr. M's wife might be neglecting him. She often finds him unclean, reporting that he has not eaten since yesterday's visit and with bruises on his arms. Mrs. M reports that Mr. M is difficult to care for, and that he lashes out at her. It is hard to know the truth here. The palliative support team recommends transfer to hospice. Mr. M insists on staying home. He says, 'If I leave, my wife will 'win' and will control everything.' However, upon further inquiry, using the prompts provided in the risk support management tool, the team came to a better understanding that what mattered to Mr. M was something completely different. What he meant by not winning required a deeper dive into his psychological world, one rife with a history of interpersonal conflict. As per best practice, the team offered resources to work toward reconciliation and healing in this area, but the client refused.

As time was running out with his progressive physical decline, the team was able to modify its approach. The team came to understand, using this positive risk approach, that it was beneficial to Mr. M not to move, and that this was a risk he was willing to take. Again, what is positive is not ultimately defined by the clinical team but by the client. In this case, he has his reasons. But, the process allowed that point to be clear as well as offered a way to carefully identify potential harms, their severity, as well their likelihood.

BUILDING A RISK SUPPORT MANAGEMENT PLAN

Once the risk has been identified, the healthcare team in consultation with the client must explore the following: consider the applicability of standard risk elimination strategies; explore risk mitigation or minimization possibilities; and develop a safety planning for the component elements of the risk that can neither be eliminated nor mitigated.

The aim of this exercise is to build a risk support management plan that reflects the positive potential benefits and the stated priorities of the client at the center of the plan itself. At every step, a risk support management plan should use all available resources and supports to achieve the desired positive outcomes and to minimize the potential harmful ones.

The case: part 2: risk management

Building Mr. M's risk support management plan required the team honor that the client's choice to live at risk was to remain in his home at this stage of his palliative care treatment.

The risk support management plan cocreated with the client involved noting that the client declined eliminating the risk by going to hospice or hospital, but agreed to minimize the risk by being willing to call for help with a cell phone. In terms of safety planning, the client also accepted some service provider limitations: namely, that if any of the care givers identified that the client's care needs exceeded their capacities and posed imminent or immediate risk issues, that they would escalate care as per best practice. It was agreed that this might include staff calling 911 for emergency support. Additionally, in this case, the client also agreed to file backup papers for hospice care just in case he needed hospice later and/or changed his mind. This decision was also entered under safety planning. Although the team felt comfortable with this risk support plan at this stage, they knew that the client would eventually lose his ability to use a phone. The safety plan's inclusion of a backup plan made staff feel better prepared but everyone agreed the client's overall choices did not reflect the approach they would have chosen for themselves.

CRITERIA TO ADOPT A RISK SUPPORT MANAGEMENT PLAN

Pragmatically speaking, not every decision to live at risk can or should be supported. There is, however, need for some form of evaluative criteria to assist the team and client in assessing the viability of any plan. The tool (Fig. 1) incorporated the following four criteria that are to be used to assist in finalizing and validating a plan: the need for consensus from all stakeholders involved; that the plan be sustainably resourced; the plan must meet safety and professional standards; and finally, that it is supported legally.

From the perspective of consensus, all parties affected by the plan, the client, family (if appropriate), the community care broker, and the direct service provider organizations, must agree/consent to the

implementation of the proposed risk support management plan. This step is important given that complex cases require that all the parties to the plan must know what they are committing to as well as live up to their assigned responsibilities. Furthermore, as home care services are optional, consent is critical.

The resource criterion requires an affirmative answer to this question: Do we have the right resources (funding, human capital, etc.) in place to implement the risk support management plan? In the context of increasingly limited funding and resources for healthcare services, this determination is a societal requirement applicable to all publically funded service providers. Publically funded services to clients are determined on the basis of eligibility, but there are fiscal and procedural limits to what can be supported. The question also asks and considers what the client or family is willing to support both financially and in terms of their own human capital. Additional services can always be purchased by clients who have the means. With this criterion, it is important not to underestimate human capital and its limitations. Caregiver burnout is an ever-increasing concern in the literature [14].

The third criterion speaks to safety standards. This is a particularly important question for regulated healthcare professionals and accredited healthcare organizations. It seeks to ensure robust conversation that the plan's proposal related to risk management does not violate staff's professional norms, industry standards, and will not implicate an organization in activities outside of its mandate related to safekeeping.

The last criterion asks: Does the Risk Support Management Plan comply with the laws and Professional Practice Standards which apply to this case? Nothing in a plan should be illegal or require participants to work outside the usual standards of care. No plan should place a certified professional at risk of losing their license to practice.

The case: part 3: validating the risk support management plan

In this case, the team checked the plan against the four validating criteria. First, the team ensured that all the relevant partners agreed to the plan. This included the client, the professional care providers, and the home care broker/manager. In this case, it was impossible to directly get consent from Mrs. M, as the client refused to include her directly in the planning. However, the plan did include offering Mrs. M psychosocial support as well as respite. Obviously, this decision by Mr. M is not ideal, but in this complex psychosocial dynamic context, the team did insist – and Mr. M agreed – that Mrs. M also has support too. In terms of the second criteria, a sustainably resourced plan was in place, with proper safeguards and clarity about what the client and team could and could not do. In terms of safety standards, this situation required that the capable client be aware of his options, including his possibility of reporting possible abuse to the authorities. It was also made clear that staff would not violate any professional standards, and would escalate care interventions if these were indicated. There was also robust discussion about how and if a duty to protect might be applied in this situation. Finally, in terms of the final criterion, in terms of the legal issues, and given the long-standing history of alleged mutual abuse, it was agreed that there was nothing here being planned that put any of the parties on the wrong side of the law. Subsequently, the Mr. M risk support plan was validated.

LIMITATIONS AND CONSTRAINTS

The study has argued that that the idea of a risk support management plan is an idea whose time has come when considering risk and safety for home care clients. The case showed that it can be applied to palliative care in the home. Nevertheless, there are some limitations. As evident from this case, the tool is not diagnostic but rather provides a structured mechanism [7▪] for the necessary considerations to deliberate over when pursuing best practice in risk management. It is important to note that in practice, the use of such risk support management tools is iterative. The tool builds in a review time frame to remind the plan builders to set a proportionally appropriate review schedule.

Furthermore, the criterion of consensus in the validation stage points to an even more important requirement for excellence in risk management, namely for a noncoercive and nonsiloed relationships among healthcare teams and partners. Finally, as noted in the introduction, the idea of positive risk approaches is still relatively new. And there are no robust systematic studies in the literature, which validate its effectiveness.

The case resolves: part 4: benefits of risk support management plan

As anticipated, Mr. M's health declined. Although still capable for treatment decision, he could no longer phone to get help if needed. His wife seemed to be increasingly agitated and would often refuse services. The nurse and the doctor were the only persons Mrs. M would let in and they worked hard to maintain their relationship. One day, while the wife was out running errands and getting some well deserved respite, the nurse engaged Mr. M again on the risks he was taking, and the safety planning agreed on in the risk support management tool. She returned to the fact that his application for hospice was still in place. She updated him on the fact that a bed had just come up and that he could accept it. Mr. M

chose to accept the bed, and was moved immediately. Mr. M died a few days later in hospice.

CONCLUSION

A risk support management plan, based on a positive approach, provides a way to support a client's choice to live at risk, anticipate for expected complications, and inform the creation of a contingency plan to address concerns as they may arise. The plan also constructively sets transparent and fair limits and justifications for why certain risk-taking behaviors might not garner the support from professional caregivers and their organizations.

The key balance with a positive risk approach is to both honor clients and respect the limitations of caregivers both professional and personal. The added value of a structured approach like the one proposed here for risk support management plans is that it provides adequate due diligence and informed decision-making when planning for risk-taking in complex situations.

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Conflicts of interest

There are no conflicts of interest.

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