

Preparative collaboration for missing persons with dementia in Sweden: a pilot study

Collaboration
for missing
dementia
patients

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Abstract

Purpose – The purpose of this paper is to give an account for preparative collaboration between the police and municipal eldercare in Sweden concerning missing persons with dementia.

Design/methodology/approach – Design/methodology/approach used was a qualitative case study design, consisting of one focus group with representatives for the participating organisations, followed by directed content analysis.

Findings – The findings showed a lack of current collaboration and reluctance to new collaborative initiatives. However, when focussing on preparative collaboration of coordinated responses to missing incidents, possibilities for improvement could be identified. The improvements concerned updated personnel response checklists, along with suggestions for an elaborate life story document in eldercare, with police access. Finally, better coordination of the return of the found person and a follow up were proposed.

Research limitations/implications – It is suggested that collaboration must be given different meanings and use different approaches adapted to the different phases in a rescue operation. In the preparation and the response phase, the focus should be on coordination of the resources available. In the pre-planning and prevention phases, as well as in evaluation and learning, horizontal collaboration is more suitable. The amount of data in this study is a research limitation which calls for further research.

Practical implications – It is suggested that collaboration must be given different meanings and use different approaches adapted to the different phases in a rescue operation. In the preparation and the response phase, the focus should be on coordination of the resources available. In the pre-planning and prevention phases, as well as in evaluation and learning, horizontal co-operation is more suitable.

Originality/value – The originality/value of this paper can be found in the novelty of missing person research in Sweden, and in practical suggestions for preparative collaboration concerning persons with dementia who go missing. Finally, it can be found in the suggested need for a more dynamic and process-sensitive view of collaboration in SAR or rescue operations.

Keywords Collaboration, Dementia, Eldercare, Missing persons, Police, Preparedness

Paper type Research paper

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Introduction

Internationally, persons with dementia constitute one of the largest and expanding groups of persons at high risk of going missing and suffering severe consequences of missing incidents (Koester and Stooksbury, 1995; Bonny *et al.*, 2016; Neubauer *et al.*, 2021). Research on missing persons with dementia is also well represented internationally in research related to ageing (Bantry White and Montgomery, 2015; Shalev Greene *et al.*, 2019; Neubauer and Liu, 2021), environmental planning (Puthusseryppady *et al.*, 2020), and research by the police on risk assessment (Ferguson, 2022). In Sweden, 25% of emergency search operations for missing persons concerns this group. Due to the illness, persons with dementia are extremely vulnerable as they are unable to navigate their surroundings or call for help and are therefore at high risk of coming to harm or dying (Bantry White and Montgomery, 2015; Shalev Greene *et al.*, 2019; Doyle and Barnes, 2020). Therefore, search operations for persons in this group are urgent. Koester and Stooksbury (1995) speak of a “search window” of 24 h for persons with dementia. After that, the survival rate rapidly falls (Adams *et al.*, 2007; Rowe *et al.*, 2011).

Emergency searches for missing persons in Sweden are rescue operations carried out by the police in accordance with the Civil Protection Act “*in those cases where there is a threat to a person’s life or where a person’s health is seriously threatened*” (Swedish Code of Statutes 2003:778, 2003, p. 778, chapter 4:4).

According to Swedish Police records from 2020, approximately 25,000 persons are reported missing every year, and 6,000 of these reports concern high risk cases (Stenberg *et al.*, 2019). Around 400 of these cases are adjudged to be immediately life threatening and lead to search operations. From the Swedish Police’s statistics (Stenberg *et al.*, 2019), in 28% of the cases the person would not have survived if they had not been found, and in 11% of the cases the missing person was found dead.

The urgency in finding missing persons with dementia makes search operations very resource- and time-consuming (Fyfe *et al.*, 2015; Sowerby and Thomas, 2017; Shalev Greene and Pakes, 2013), emphasising the need for collaboration.

Both internationally and in Sweden, research on collaboration indicates the need for further development. Patterson and Swan (2019) show there is a need for better integrative collaboration between the police and social services in the USA and note that existing brand models for this were not used. In Sweden, Danielsson (2016) indicates the need for clarifying roles and responsibilities in cross-sector professional collaboration, due to differences in procedures and situational understanding. Finally, Scandinavian multi-agency collaborative rescue exercises are criticised for not reaching stated objectives and for lack of efficiency (Berlin and Carlström, 2009, 2015; Sørensen *et al.*, 2018).

Regarding prevention, risk management and response to missing persons with dementia, efficient collaboration amongst agencies, such as social services and police (Hayden and Shalev Greene, 2018), or with volunteers, is central. Research has also been carried out on collaboration with persons with dementia to prevent them from going missing by means of guidelines and by conducting interviews regarding well-being once they have returned home (Neubauer *et al.*, 2021). Another important research field is collaboration with and the provision of support to relatives as they attempt to cope with the *ambiguous loss* of their loved ones (Wayland, 2019).

Scandinavian research on search and rescue (SAR) collaboration and missing persons is limited. Torkildsen (2009) studied the behaviour of missing persons, including persons with dementia, Berg (2016) studied police search procedures, and Stenberg *et al.* (2019) carried out an international literature review of the entire fields of missing persons. Larsson (2021) established missing persons with dementia as the objective of a literature review. Stenberg (2022) discussed collaborative practices and perspectives in SAR operations and concluded

that the collaboration must be adapted to the prevailing uncertainty and the need for haste when there is a life at stake.

However, research about persons with dementia in risk of going missing in Scandinavia is still a novel field in need of development. The collaboration between the police and eldercare about persons with dementia at risk of going missing is therefore the object for this study.

Purpose

The purpose of this paper is to give an account for preparative collaboration between the police and municipal eldercare concerning missing persons with dementia in Sweden. The research questions are:

- (1) How do the studied organisations prepare for missing persons cases regarding procedures and collaboration?
- (2) Which improvement possibilities can be identified when focussing on preparative collaboration between them?
- (3) How can a process perspective of phases and different collaboration perspectives improve collaboration in a missing person case?

In the introduction, the problem and the purpose of the paper are stated. This is followed by methodology and a theoretical framework. The findings from the focus group interviews are subsequently described and discussed. Finally, conclusions and suggestions for further research are presented.

Theoretical concepts

Central concepts as dementia, missing persons and collaboration perspectives are presented, defined and discussed below.

Dementia

Dementia (cognitive impairment) is a collective term for multiple related irreversible disorders affecting the brain (Denning and Sandilyan, 2014; Gale *et al.*, 2018). In Sweden, approximately 160,000 people are currently diagnosed with dementia. The number is expected to increase to 270,000 by 2030 (The National Board of Health and Welfare, 2018). Six out of ten people with dementia report becoming lost (American Alzheimer's Association, 2011). Persons with dementia wandering off, with increased risk of becoming disoriented and getting lost is a well-known phenomenon (Adams *et al.*, 2007; Bantry White and Montgomery, 2015). A total of 38% of those persons are expected to go missing more than once (Tarling and Burrows, 2003; Gibb and Woolnough, 2007; Ferguson and Picknell, 2021). Both prevention and preparations for efficient response are of extreme importance to prevent suffering or death, as well as in reducing the societal costs.

Missing persons

A missing person is defined as “*anyone whose whereabouts cannot be established and where the circumstances are out of character or the context suggests the person may be the subject of crime or at risk of harm to themselves or another*” (Association of Chief Police, 2013, p. 5 in Bonny *et al.*, 2016, p. 297). This includes a variety of situations like becoming lost, or becoming a victim of crime, being suicidal or depressed, or seeking solitude for some time. A missing person with dementia can go missing as a result of several of these categories, and is always

assessed as a person at high risk (The Swedish Police Authority, 2016; Stenberg *et al.*, 2019), and becomes the subject of an emergency search operation. The sooner the missing person is reported to the police and the more relevant information the police have access to about the person, the better the chances of locating them swiftly (The Swedish Police Authority, 2016; Stenberg *et al.*, 2019).

Collaboration perspectives

A common definition of collaboration is the shared use of different actors' resources to accomplish something agreed on (Enyedy and Stevens, 2014; Stenberg, 2022). Gulati *et al.* (2012) distinguishes between collaboration from *cooperative* perspectives or from *coordination* perspectives. In Scandinavia, the cooperative perspective dominates both research and practical collaboration (Axelsson and Bihari Axelsson, 2006), especially concerning research in rescue collaboration, crisis management and collaborative rescue training (Berlin and Carlström, 2009, 2015).

Cooperation perspectives focus on policy agreements, shared meanings and long-term relations between different organisational actors with the aim of achieving shared objectives or benefits, which solitary actors cannot achieve alone (Berlin and Carlström, 2009, 2015; Kalkman and de Waard, 2017; Kristiansen *et al.*, 2017). Collaboration from this perspective is aimed at what is called *horizontal cooperation* (Sørensen *et al.*, 2018), which places emphasis on equal workloads, influence as well as democratic principles (Berlin and Carlström, 2009, 2015; Kristiansen *et al.*, 2017).

The *coordination* perspective (Gulati *et al.*, 2012) emphasises the coordination processes and activities for combining and coordinating resources for cost efficiency or functionality. Jahre *et al.* (2009), describes this as vertical coordination in creating or changing a process in terms of a supply chain or a rescue chain focussed on a flow from a point of origin to a point of delivery. This perspective (Kaneberg *et al.*, 2016; Jahre *et al.*, 2009; Tatham and Spens, 2016) is well represented in collaborative practice in rescue and crisis response and in international research in emergency or crisis management including urban SAR. Viewed from this perspective, a rescue chain has different steps, which must fit into each other to complete the mission, conduct the rescue operation or find the person, and it is possible to categorise the steps as "before", "during" and "after". Preparedness is then identified as a key step in this chain, where stable structures such as organisational actors combining and coordinating their resources to manage shared needs and unpredictable and stressful events (Kaneberg *et al.*, 2016; Tatham and Spens, 2016). The quality of operations is usually set in this step relating to preparations for switching from everyday operations to emergency response (Jahre *et al.*, 2009; Kaneberg *et al.*, 2016).

Methodology

The study was part of a larger project with the purpose of analysing collaboration in missing persons operations in Sweden (Stenberg *et al.*, 2019). It was carried out with a qualitative case study approach (Alvesson and Sköldböck, 2018) targeting two of the key services in operations relating to missing persons with dementia: the police and municipal eldercare (Stenberg *et al.*, 2019).

To explore collaborative practices and possibilities, a focus group interview (Robson, 2002) was conducted in a meeting between representatives from the police and municipal eldercare in southern Sweden.

The participants in the focus group were represented by two male police officers from local and national level in the Swedish Police (P1 and P2), one female and one male senior manager in social care (M1 and M2) and one male municipal safety officer (MSO1).

The focus group interview was designed to discuss and compare experiences, routines and procedures from a collaborative perspective. Themes such as “prevention/preparation”, “collaboration” and “the return of a missing person” were initiated based on the literature review from [Stenberg et al. \(2019\)](#), which showed a lack of knowledge about what happens from a collaborative perspective before, during and after a missing incident. That formed the structure of, and the themes for the discussion. The participants were asked to reflect and elaborate on the themes from their experiences, and further expand the themes in the discussion.

The focus group interview lasted two hours and was digitally recorded, transcribed verbatim and notes were taken. It was followed up by e-mail and the minutes were sent to the participants for comments and approval.

Directed content analysis ([Hsieh and Shannon, 2005](#)) was used for analysis. The same structure (before, during and after), and the original themes, mentioned above, were used as framework for coding the data into developed and elaborated themes in [Table 1](#):

Finally, former studies in this field, and theories on collaboration were used for discussing the elaborated themes further in the discussion.

Findings

When the police officers and the social care managers met, they expressed they had little knowledge of how “the other” professionals worked. Before the meeting, representatives from both organisations made it clear that there was no intention to start any development projects in this field. “*My employees work so hard. I do not know what they would do if I asked them about one more project . . . but one meeting for information exchange is fine*” said the head of the eldercare organisation. The focus group interview was therefore the first opportunity for the respondents to meet and discuss mutual points of interest in their professional work relating to missing persons with dementia.

According to the respondents’ discussion based on the research questions and introduction given, the following themes were identified: (1) cut downs, (2) life story documents, (3) checklists when someone is missing and (4) the return of the found person and ending of the SAR operation.

Themes introduced in the focus-group	Subthemes	Elaborated themes
1) Experiences, routines and procedures	Lack of knowledge of how the other actor work	Consequences of cut downs Lack of knowledge of sources of information
2) Prevention/preparation	The importance of time Intention not to disturb the police The order of activities	Checklists of activities in missing person cases Life story documents
3) Collaboration	Lack of resources, time and motivation for collaboration	No intention to start developing collaborative work practices
4) The return of the found person	Contact needs with other agencies out of office hours Methods to meet anxiety of being returned by the police	Collaboration for information sharing and anxiety reduction in the return

Source(s): Author’s own creation

Table 1.
Introduced themes,
subthemes and
elaborated themes

Cut downs

When describing their organisations and work, cut downs in both sectors were discussed as central. A mutual problem was described as “*we are sufficiently busy already*” (M1) and that preventive activities are not prioritised. “*We don’t do any preventive work but act in accordance with the action plan or checklist once something has already happened*” (P1).

Life story documents

In accordance with guidelines from [The National Board of Health and Welfare \(2018\)](#), a “life story” of a person’s earlier life is documented when a person with dementia moves to special housing—to raise the quality of the person’s care ([Clarke et al., 2003](#)). This should be standard procedure in all eldercare facilities in Sweden, yet there are no common standards for the content, updates, or the access to this document. The document contains information on daily routines, food preferences, et cetera. Compared to relevant information for the police, it lacks information on former places of relevance to the person: houses, workplaces, schools, places of personal significance, et cetera. The police respondents claimed they had no knowledge of and no access to this systematic source of information. On the other hand, the eldercare managers did not know of the document’s potential value to the police.

Checklists

When a person goes missing, the eldercare organisation has a checklist with instructions to follow:

- (1) Start the search for the missing person immediately since temperature and weather can make it urgent.
- (2) Gather the work group to discuss what happened before the person went missing. Who saw the person last? How was the person dressed? How did the person feel?
- (3) Search the premises and find out if the person can be somewhere in the building or in the nearby surroundings.
- (4) Inform the manager of the unit and the relatives that the person is missing.
- (5) Find out if the person can be in what was previously the person’s home.
- (6) Find out if the person can have accompanied relatives or other visitors.
- (7) Alert the police as per the telephone list. Describe what the person looks like, clothing and other significant features.” (X municipality)

In a discussion about when to contact the police, the respondents from eldercare felt that they first wanted to make sure that they could not find the missing person by themselves. A missing person with dementia is often found close to where the person is expected to be, and the personnel did not want to alert the police needlessly. The police officers on the other hand, strongly suggested another prioritisation:

It is important that we are contacted directly. If we let the missing person move two kilometres instead of one kilometre, the area to search for is not twice as big, but four times larger. The factor of time is crucial . . . This (the instruction to alert the police) needs to be much higher up. Our suggestion is that you move this to number two in your list (P1).

The police officers explained that most cases are quickly resolved. Three out of four cases are resolved in 3–4 h, and after six hours only 25% of persons with dementia reported missing remain missing. The longer it takes, the less chance there is to find a missing person with dementia alive, he claimed.

The return

The police respondents agreed that valuable information easily could get lost after a search without an appointed contact person or time for doing this. This was raised as a problem since the police normally leave for other duties as soon as the search is ended. *“The search can be over at four a clock in the morning and a lot of other things can happen before I return to my desk and then it is time to go home if I have worked the night”* (P1).

One respondent suggested that the rescue services’ internal command officers could function as mediators for essential information exchange.

Furthermore, the manager from eldercare expressed that when the police return a person to a special housing after a missing incident, contact with the police could cause even more disorientation than the missing incident itself. A suggestion from the respondent was that the police could arrange the return of the person in contact with eldercare.

Discussion

The findings are discussed and analysed below from a collaborative perspective, and horizontal and vertical collaboration are contrasted and compared to their usefulness for preparative collaboration. Finally, methodology considerations are discussed.

In the findings, the participants pointed to the absence of information sharing or collaboration concerning missing persons with dementia between the police and municipal eldercare for many years in this region, despite collaboration being a core assignment for Swedish authorities and municipalities, as stated in the Swedish Police Act ([Polislagen, 1999](#)) for example. On one hand, the findings can be viewed as problems emanating from the lack of knowledge of each other’s procedures. On the other hand, this means improvements can be identified if this lack of knowledge and collaboration can be resolved.

A comparison of the content in existing life story documents ([The National Board of Health and Welfare, 2018](#)) and the information vital for finding a person with dementia ([The Swedish Police Authority, 2016](#)) showed some overlaps and the document could easily be supplemented with relevant information concerning the missing person and made accessible and known to the police.

Adapting the missing person checklists for eldercare was quickly done by the eldercare managers when they realised that the time factor and swiftly alerting the police were paramount ([Koester and Stooksbury, 1995](#); [Adams et al., 2007](#); [Rowe et al., 2011](#)). Such coordination is free of cost and will likely save resources if there is awareness of the need for change.

Finally, the participants suggested coordination between the Police, the municipality and relatives when a missing person with dementia is found and returned. Information from the search can be valuable for preventing the person from going missing again, which happens to more than a third of missing persons ([Harris and Shalev Greene, 2016](#)). If this recurrence could be prevented, lives can be saved, along with societal costs.

Resistance to collaboration

Although the indicated merits of collaboration, the findings demonstrated no initial desire to collaborate, even when the lack of knowledge about other central professional actors’ ways of operating were clearly shown to affect the respondents’ own work and its efficiency. Other reports by [Andersson and Lindström \(2017\)](#) and [Stenberg \(2022\)](#) confirm that collaboration is perceived as challenging and time consuming and even avoided.

Reasons for resistance can be found in a tradition of cut downs and organisational changes influenced by New Public Management, NPM ([Hood, 1995](#); [Wolmesjö, 2005](#)), a lack of competence and knowledge of “the other”, as well as new demands and obligations ([Wolmesjö and Solli, 2021](#)).

Horizontal cooperation does not fit with response organising

Another reason could be found in the meaning of collaboration to the respondents and to their organisations. The Scandinavian tradition (Berlin and Carlström, 2009, 2015), emphasises horizontal cooperation based on integration and shared values in plans, objectives and long-term relations. Stenberg (2022) discusses how a reason for not collaborating, when it comes to rescue, can be found in the lack of fit between meetings that are experienced as time consuming and unproductive, and at the same time, demands on efficient and swift response to emergencies characterised by time pressure and uncertainty.

Vertical coordination as a rescue chain

Another perspective on collaboration is to aim for vertical coordination of needed activities and resources in a supply chain in several steps (Kaneberg *et al.*, 2016; Tatham and Spens, 2016). This fits better with the way rescue response is sequentially organised in chains of activities carried out in turn by different specialists, which makes it easy to identify steps in a coordination process.

A timeline of collaboration

In crisis management, separate phases such as preparation and recovery are identified (Shaluf *et al.*, 2003; Olorunfoba *et al.*, 2018) and require responses adapted to the specific phase. It is here suggested that collaboration should also be dynamic and adapted to fit the specific rescue operation phase it is meant to support. For example, during ongoing search operations, there is no time to discuss shared values or democratic influence. At that stage, the focus must be on coordination of resources for a speedy response.

According to the respondents, in preparing for a response the collaboration should focus on coordination and not on inventing new ways of organising. Instead, the respondents could improve their preparation by comparing procedures they have already used and better coordinating them. This was shown to be done after just one meeting.

However, it is suggested here that horizontal collaboration should be carried out in the planning and prevention phases, as well as in the final phases of collaboration: evaluation and learning. During those phases, there is not the same degree of time pressure and their purposes include elements of creation and invention, such as on improving methods, long-term development and relationship building.

Contributions

The practical contributions of the study were found in improvement possibilities in coordinating procedures which already were in use. This applied to checklists, life story documents and better return routines.

The theoretical contribution of the paper is threefold. First, it gives an account from a novel research field relating to missing persons research in Scandinavia, which needs to be further developed. Second, it challenges the Scandinavian horizontal collaboration ideals of shared professional situation understanding (Danielsson, 2016), and multi-agency training (Berlin and Carlström, 2015; Sørensen *et al.*, 2018) as the only efficient way to collaborate in rescue response and crisis. Third, it shows the need for a more dynamic and process-sensitive use of collaboration. Here it is suggested that the collaboration is adapted to the steps in processes in the rescue it is meant to support and that a preparative collaborative phase is identified. This need for flexible approaches is supported by the reported choices of unique local solutions although more generally approved models exist (Patterson and Swan, 2019).

Methodology considerations

A limitation with this study is the size of the data sample. Only one focus group with five respondents participated in this study. Even though the sample is small, the result is data rich. Preliminary results have been discussed with and validated by other representatives from the police and municipal eldercare to ensure the reliability of the study.

Conclusions

Both the police and eldercare is required by law to collaborate in Sweden, but there is a lack of preconditions and know-how, which makes collaboration difficult or even perceived as meaningless, and to be avoided. The lack of collaboration impacts efficiency in the search for missing persons with dementia.

A conclusion is that efficient collaboration must be given different meanings and use different approaches adapted to the different phases in a rescue operation. In the preparation and the response phase, with uncertainty and time-pressure, the focus should be on coordination of the resources available. In the pre-planning and prevention phases, as well as in evaluation and learning, horizontal collaboration is more suitable.

By focussing on the phase of preparative collaboration in the search for missing persons with dementia and by comparing and coordinating procedures, which already were in use by the respondents, possibilities for practical improvements were identified.

- (1) Checklists for what to do when a person in eldercare goes missing need to be updated to reduce the time it takes to alert the police and to locate the missing person.
- (2) National life story documents should include vital and information accessible to the police in case of a missing incident.
- (3) Procedures for information sharing and coordination for the return of a found person to prevent recurrence.

Suggestions for further research

This study can be considered a pilot study in a new field of research about missing persons. The size of the study indicates the need for further research to validate and elaborate on the results.

The study points to extensive needs for understanding collaboration as a manifold of organising principles for different purposes. Theoretically, collaborative strategies and models for collaborative preparedness need to be better understood, evaluated, and developed for various uses in different contexts and from different perspectives. Of special importance for the organising of SAR is understanding the types of demands uncertainty and stress place on efficient collaboration. Finally, the context of missing persons with dementia needs further studying from and between several perspectives.

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Collaboration
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