


**RESEARCH ARTICLE**

# An interview study of the care manager function—Opening the door to continuity of care for patients with depression in primary care

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**Abstract**

**Aim:** To explore experiences among patients with depression of contact with a care manager at a primary care centre.

**Design:** A qualitative explorative study.

**Methods:** During spring and summer 2016, 20 individual face-to-face interviews were conducted with patients with experience of care manager contact. The material was analysed using systematic text condensation.

**Results:** The participants described that having contact with a care manager was a support in their recovery process. Care became more available, and the structured continuous contact and the care manager's availability contributed to a trusting relationship. Having someone to share their burden with was a relief. However, it was described as negative when the care manager was perceived as inflexible and not open to issues that the participants felt a need to discuss. For the care manager contact to be successful, there is a need for flexibility and individually tailored contact.

**KEYWORDS**

care manager, depression, patients, primary health care, qualitative study

## 1 | INTRODUCTION

Depression causes deep personal suffering involving decreased quality of life and well-being (The Swedish National Board of Health & Welfare, 2017; Villoro, Merino, & Hidalgo-Vega, 2016; World Health Organization, 2013). Further, there is an increased risk of poor adherence to medical treatment (Ciechanowski, Katon, & Russo, 2000) and depression may increase the risk of suicide (Donohue et al., 2014; Harwitz & Ravizza, 2000; Wang et al., 2015). The negative consequences following depression not only affect the life situation of the patient, but also that of any children struggling to cope with the stress of parental depression (Jaser et al., 2007, 2005; Langrock,

Compas, Keller, Merchant, & Copeland, 2002). The growing number of persons with depression leads to financial strain on the primary care system as well as on workplaces; when individuals with depression are on sick leave or present at work despite depression, this affects workplace productivity (Aronsson, Gustafsson, & Dallner, 2000; Evans-Lacko & Knapp, 2016). It is important to find strategies to improve treatment and care for patients with depression, since it is one of the most common diseases in the world (World Health Organization, 2013). Collaborative management strategies where understanding of depression is shared between professionals and patients may help improve care for patients with depression (Coventry et al., 2011).

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## 1.1 | Background

Depression is one of the most common diseases among patients in primary care (Bilsker, Goldner, & Jones, 2007; The Swedish National Board of Health & Welfare, 2017). According to both global recommendations and Swedish national guidelines, patients with depression should be offered psychotherapy, accompanied by medical treatment when needed (The Swedish National Board of Health & Welfare, 2017; World Health Organization, 2013). However, the increase in the number of patients with depression suggests that there is a need to improve treatment for these patients. Implementing a care manager (CM) at the primary care centre (PCC) has previously shown positive effects such as faster recovery and reduced symptoms for patients with depression (Gallo et al., 2013; Garrison, Angstman, O'Connor, Williams, & Lineberry, 2016; The Swedish Council on Health Technology Assessment, 2012). A collaborative care organization, such as a CM organization, has also shown cost-effectiveness for health care (Johnson et al., 2014; Kates & Mach, 2007; Rost, Pyne, Dickinson, & LoSasso, 2005; Wang et al., 2007). A CM works at the individual level, staying in regular contact with and monitoring the patient, as well as at the organizational level, coordinating and facilitating multidisciplinary collaborative care at the PCC. The CM also constitutes a support for colleagues by focusing on the development of guidelines for treatment for depression, etc. The CM function is an addition to regular care and treatment and does not replace other treatments (Johnson et al., 2014; Kates & Mach, 2007; The Swedish Council on Health Technology Assessment, 2012; Wang et al., 2007; Williams et al., 2007).

When developing care for patients with depression, qualitative studies describing patients' experiences and perceptions are crucial if person-centred care is to be achieved (Keeley, West, Tutt, & Nutting, 2014; Rittenhouse & Shortell, 2009). It is important to explore how patients have experienced the contact with a CM to gain a deeper understanding of positive and negative aspects of the contact. However, there is a lack of qualitative studies where patients with depression are asked to describe their experiences from having contact with a CM. Therefore, the aim of this study was to explore experiences among patients with depression having contact with a care manager in primary health care.

## 2 | THE STUDY

### 2.1 | Design

This is a qualitative study where individual face-to-face interviews were conducted and analysed using systematic text condensation in accordance with Malterud (2012). The study is a qualitative follow-up of a cluster randomized intervention, previously described by Björkelund et al. (2018), where a CM organization for patients with depression was implemented and evaluated for the first time in Swedish primary care settings. Promising quantitative results from the intervention have previously been reported about reduced depression symptoms, improved quality of life and return to work for

patients with a CM contact (Björkelund et al., 2018). In addition, a qualitative follow-up showed that nurses/district nurses working as CMs perceived their work as more meaningful and empowering when able to provide care continuity and accessibility to patients with depression (Svenningsson et al., 2018).

### 2.2 | Setting

This study was conducted in primary care, in both rural and urban areas, in Sweden. At PCCs, there are various professionals, such as nurses, GPs, physiotherapists, occupational therapists and psychotherapists. For a person with a health-related issue, the PCC is often the first healthcare contact. This means that many people seek contact with primary care and for many different reasons, including depressive symptoms. The PCCs in this study were either privately run or run by county councils. All CMs were nurses, one at each PCC, who devoted around 8 hr a week to the CM function.

### 2.3 | Participants

Twenty participants, 12 female and 8 male, 18–65 years of age (mean 44, median 44), from both urban and rural settings, were recruited to this study. A purposive sampling was used (Malterud, 2012) to select patients from PCCs with a CM. The participants were the first 20 patients in the cluster randomized intervention study to have contact with a CM and had all been diagnosed with mild or moderate depression at a PCC. They had been in regular contact with a specially trained CM for 3 months as an addition to their care as usual (CAU), that is, cognitive behavioural therapy (CBT), interpersonal therapy and/or antidepressants, in accordance with The Swedish National Guidelines for Depression and Anxiety Disorders (The Swedish National Board of Health & Welfare, 2017). Their contact with the CM followed a structured protocol based on an initial 1-hr dialogue at the PCC, followed by 6–8 scheduled telephone contacts (each lasted around 15–30 min) within 3 months (Björkelund et al., 2018; Svenningsson et al., 2018). Every telephone contact started with the patient filling out the self-assessment instrument MADRS-S (Montgomery Asberg Depression Rating Scale – self-rating version; Svanborg & Asberg, 1994).

### 2.4 | Procedure

The participants recruited to this study had all been in contact with a CM at one of the PCCs where a CM organization was implemented. When they first agreed to take part in the intervention study evaluating CMs at PCCs (Björkelund et al., 2018), they were also verbally informed that they might be asked to participate in an interview later, where their experiences of having contact with a CM would be the focus. When filling out the instruments at the 3-month follow-up, the first 20 participants were asked, face-to-face, if they were interested in taking part in an interview. If a participant answered yes, an interview took place either then and there, at the PCC, or was scheduled for later.

## 2.5 | Data collection

Twenty individual interviews were conducted in spring and summer 2016. Since the first interviews were not as rich as expected, more interviews than planned were conducted. The view taken by Malterud (2012) was that when exploring individuals' experiences, a full range of potential available experiences or phenomena cannot be covered. Instead, Malterud (2012) suggested that a limited number of participants would provide sufficient data for analysis. In our study, every narration was unique; however, the participants described similar experiences and perceptions, and therefore, "saturation" was considered achieved. The interviews took place either at the PCC, at a university, or in the patient's home, as determined by the patient. The interviews were guided by a semi-structured interview guide (Kvale, 1996), containing questions such as: "Could you please describe your experiences from having contact with a CM?" "Could you please describe how you have perceived the CM function?" Follow-up probing was used, for example: "Please, tell me more," or "Could you please give an example?" The interviews lasted around 15–45 min, were tape-recorded and transcribed verbatim.

## 2.6 | Data analysis

The qualitative data were analysed using systematic text condensation (Malterud, 2012). Systematic text condensation, influenced by Giorgi's phenomenological method (1985), was found suitable for the study aim and the nature of the data. The analysis was collaboratively performed by three of the authors (CU, IS and ELP) and was kept close to the participants' actual expressions, without seeking to interpret their narrations at a deeper level. Every step in the analysis was critically discussed in depth among the authors, to avoid bias due to pre-understanding. As a first step, the authors separately read the text in its entirety, to obtain a first overall impression and to note preliminary themes. With the preliminary themes in mind, the authors identified meaning units concerning patients' experiences of having contact with a CM. Code groups were established, and the meaning units were sorted accordingly. Within each code group, sub-groups were identified highlighting important parts. Condensates from each group were synthesized to form general descriptions of the patients' experiences, still keeping their original narrations and terminology.

The authors of this study have different pre-understandings due to different professional and clinical experiences. CU is a trained social worker, IS and MJ are registered nurses, CB and DH are general practitioners (GPs), and ELP is a trained occupational therapist. All authors have long experience from working in health care and with patients with depression. Four of the authors (IS, CB, DH and ELP) have worked at PCCs. The authors' different perspectives and different professional backgrounds contributed to both an inside and an outside perspective and a contextual understanding about primary care.

## 2.7 | Ethical considerations

Prior to the interviews, written and verbal information was provided about the study and participants were given the opportunity to ask questions. It was emphasized that study participation was voluntary and that participants could withdraw from the study at any time, without any consequences. The researchers were experienced in interviewing vulnerable groups and made an effort to be as observant, sensitive and respectful as possible during the interviews. If a participant was in need of emotional support, the researcher was prepared to guide and assist the participant. All participants gave informed consent. Research Ethics Committee approval was granted by the Regional Committee for Medical Research Ethics in Gothenburg (Dnr 903-13, T403-15, T975-14).

## 3 | RESULTS

The participants openly described their experiences of having contact with a CM at the PCC due to depression. They described that care had become more available to them and was coordinated by the CM. Further, they stated that the structured continuous contact and the CM's availability contributed to a trusting relationship with the CM, which in turn alleviated their burden, as they had someone to share it with. The need for clear introductory information about the CM function was emphasized so they would know what to expect, thus avoiding unnecessary anxiety. Overall, the participants described the CM contact as a source of support in their recovery. However, negative aspects were also mentioned. For example, the CM was sometimes described as inflexible and overly dependent on the self-assessment instrument MADRS-S alone, not being open to dialogues about issues the participants felt a need to discuss. The findings will be further elaborated below (see Table 1) and illustrated by quotations from the patients' narrations.

### 3.1 | A trusting relationship in which the burden is shared

A trusting relationship was described as the foundation of the CM contact. The continuity and scheduled regularity of telephone calls contributed to building this trusting relationship with the CM. The participants described feelings of alleviation from knowing they could contact the CM between the scheduled telephone calls as well, if needed. However, they rarely did. Knowing when the next contact was scheduled made it possible for them to wait:

I think the CM contact was very good. There was no hassle and it worked smoothly, making everything easier. I got a telephone number from the CM, probably straight to her telephone, so if I needed anything, or had any questions, I could easily call her. But I never needed to. The scheduled telephone calls were

**TABLE 1** Examples of meaning units, codes and subcodes

Meaning unit	Code	Subcode
<p>You aren't as exposed with a personal contact, it's good to be able to tell someone how you feel and how things are going. Here you have someone who you trust and who knows a little more about what hasn't been all that good. That it's the same person and that you plan for what is coming and what will happen.</p> <p>Your fall has been broken. I have really felt that I've been taken seriously. You feel that you have a little value. It's easy to be forgotten. Now you have a contact all the time and there's someone who cares. That has helped me.</p>	A trusting relationship in which the burden is shared	Trusting relationship
		Shared burden
<p>The care coordinator's role, to me, is that there has been a continuity. That it feels like it has gotten easier to see the bigger picture</p> <p>It feels like you've sort of gotten into the network somehow and been allowed in. You get feedback, which I think is very comforting to have. Because you feel quite lonely and you don't get in touch with people when you feel the way to do; you have to be contacted.</p>	Opening the door to continuity	Continuity
		Maintaining care contact
<p>I had to reflect on my situation every time before they called me and it felt like it could be a good way to catch up on your own thoughts, when you notice that they are starting to drift off somewhere.</p> <p>The CM contact has been supportive. Even though I'd been to the doctor, it wasn't until I met the CM that I understood that it was a depression.</p>	Supportive coordination contributing to self-reflection	Self-reflection
		Support and coordination

enough, although it was good that I was given the opportunity just in case. (Interview 2)

The participants described that the CM listened, took them seriously and sometimes gave concrete suggestions for coping with various issues, for example, physical activity. They stated that it was important that the follow-ups were the CM's responsibility, so that no further burden was added to their already strained situation. Lacking the strength to demand help and support was described as a symptom of the depression and it was important that the CM did not give up on them or lose contact, even if they themselves sometimes felt like giving up:

Being remembered by someone is a great support. Not being forgotten and being monitored over time feels very good. It is supportive and encouraging, you might say, that someone pushes you and encourages your self-confidence. (Interview 8)

It was a relief for the participants that they did not have to repeat their personal story over and over to different professionals. The CM, who was familiar with their situation, spoke to other professionals for them. The participants emphasized their relief at not having to share their story with many different people, since depression was connected to feelings of shame:

A CM contact is good, because it is really hard to have to talk to different doctors, telling your story over and over again. I feel more confident with a coordinator who has knowledge of the situation. (Interview 16)

The participants said that sharing their burden with the CM was a relief that helped them and alleviated their situation. The CM acted as a sounding board, that is, a person with whom they could raise issues and who gave them feedback. The participants described the CM as someone who broke their fall and who was like a "lifebuoy" for them:

The contact with a CM is really important. When you don't have the strength to connect with people, then it is important that there is someone other than just the doctor. Everything is difficult when you are in this situation and then the CM is like a lifebuoy. I think it has been great. (Interview 17)

The CM was described as a source of support relevant to their individual situation. For example, if needed, the CM contacted the GP about, for example, medication alterations or sick leave. The participants emphasized how important it was that the CM contact was introduced as early as possible and that information was clear, so that they knew what to expect from the CM. It was sometimes described by participants as unclear whether the CM replaced other care contacts or interventions, or if it was an addition to regular care. Also, when first being offered a CM contact, some participants had expressed worries that the CM contact would mean an increased burden and unrealistic expectations of rapid recovery, which made them anxious. This anxiety diminished once they met the CM. The participants said that it was important to discuss the function in detail and to clarify what was expected of both parties:

In the beginning, when they asked if I wanted to have contact with a CM, it felt more like a burden and something that would take time and strength. Then it

turned out to be a support, based on the regularity of contact. (Interview 1)

### 3.2 | Opening the door to continuity

Participants described the CM as “opening the door” to care and as a “conduit” into the PCC. The CM made care available to them as patients. When the participants were reassured that they had access to care if needed, they felt acknowledged, taken seriously and secure in the knowledge that they would not be forgotten:

I feel the CM has been like a conduit into the health-care center and to receiving support. It is so easy to be forgotten... I've been in this situation before, many years ago and then the focus was only on medication. It was really tough compared with today when I have received this kind of support. The support from the CM has been really great. Otherwise, without this contact, there is a risk of being forgotten while waiting for an appointment. (Interview 13)

The participants described the CM as someone who kept track of them, gave them access to care and provided support by staying in touch over time. The patients said they were grateful that someone was on their side, believed in them and spoke for them in the care system. The CM was also described as a facilitator of contact with other professionals, mainly the GP:

What has felt good is that you are not forgotten and that there is continuity and that you have a continuous contact over time. (Interview 8)

The participants stated that they found themselves in an unstable life situation, not knowing if or how they would get well. Their situation involved anxiety, emotional strain and feelings of uncertainty. It was described as important and very supportive that one and the same person followed them over time. The regular contact with the CM contributed to continuity in care and constituted a fixed point in their lives. The structured and systematized contact with the CM helped provide a sense of control in an otherwise uncertain situation:

The CM has provided continuity and has contributed to being able to see the bigger picture in the situation. The regular contact has contributed some steadiness in life... (Interview 18)

Although the structured and planned contact was described as positive, the scheduled contacts were also described as being too rigid. Some participants said that the contact should be more flexible, with regard to both the number and the frequency of contacts. The close contact in the beginning was considered important by the

participants. However, although most participants agreed that the telephone calls could become sparser as they began to recover, some participants found that the contacts became too sparse too quickly:

The only negative aspect is that the CM contact ended too soon and too fast. (Interview 2)

### 3.3 | Supportive coordination contributing to self-reflection

The CM was described as being “at the heart of things.” Participants said the CM coordinated care and collaborated with other professionals, which helped reduce the number of care contacts. For example, the CM could coordinate with the GP, so that the patient did not have to try to reach the GP, which was perceived as important. The CM was also described as compensating for poor care contacts:

Somehow care was coordinated. I don't know if it was in the records, or if they had spoken to each other. In any case, the doctor was very well informed, which I really appreciated. (Interview 17)

Having contact with the CM meant that they did not have to repeat their personal story to many different professionals. Instead, the CM constituted a link to other professionals and, with the patient's permission, could tell their story, for example, when discussing with the GP. The participants said they could discuss an issue with the CM, who then coordinated care. It was described as positive that they knew who to turn to and how, if needed:

The CM contact has felt reassuring and has been good for me. The CM is there for you, because sometimes it's difficult when you don't have the strength to try to get in touch with someone at the healthcare center. Being able to reach a certain contact person, like the CM, has felt reassuring. It has really been a comfort to know that you can turn to the CM instead of having to talk to all sorts of people who are not familiar with my situation. (Interview 11)

Having regular contact with the CM increased self-reflection and helped participants sort through their thoughts. Both the regularity of scheduled telephone calls and the repeated self-assessment instrument contributed to increased insight into depression and their personal situation:

The fact that she has called me up and asked these questions all the time has made me think about the results of the questions. It has been very good. It's probably most useful for my own reflection, getting an insight into the depression and myself. (Interview 14)

The participants described that they prepared for each telephone call by reflecting about their current mood and their overall situation:

For me, the CM contact has meant regular telephone calls and filling out these forms has meant that I've had to reflect on my situation. And it can be good to catch up on your own thoughts, when you notice that you start to drift off. (Interview 18)

Participants said that filling out the MADRS-S helped them see even small nuances in their recovery. However, they also emphasized that the self-assessment instrument must be used as a complement to further discussion, since MADRS-S did not identify everything and did not suit everyone:

Filling out the instrument was a bit negative since you could miss things, that is: you risk missing the most relevant nuances for me personally. (Interview 6)

Using a self-assessment instrument too rigidly, that is, if the CM focused only on the instrument and was not open to other discussions, was considered negative by the participants. If the instrument was used as a complement in the CM contact, for example, for initiating further discussions, the CM contacts were described as contributing to self-reflection and increasing the participant's understanding of the depression in general, as well as their individual situation.

## 4 | DISCUSSION

This study explored patients' experiences of having contact with a CM at their PCC. The main finding was that the patients felt that having contact with a CM had a positive impact on their situation. However, when the CM was overly dependent on the self-assessment instrument, leaving no room for an open dialogue, it was considered negative. Further, some wanted the number and frequency of CM contacts to be more flexible and more adapted to their individual needs and preferences.

The patients' experiences of having depression involved anxiety, emotional strain and feelings of uncertainty. Being acknowledged as a person with individual needs and preferences seems to be a crucial part in recovery. There is a universal value for patients in being listened to with empathy and personal attention (Bensing et al., 2011). This is important to consider when developing treatment for patients with depression in primary care. For example, the patients in our study emphasized the positive impact of being acknowledged and listened to. They regarded the relationship with the CM as trusting. Trust has previously been found to be important, as the relationship with the care provider influences how a patient manages their depression and affects their view of themselves (Percival, Donovan, Kessler, & Turner, 2016). Because of their vulnerable situation, it is important for patients to know what to expect and how the care is planned with scheduled contacts, since this also improves recovery (Garrison et al., 2016). If the care process is explained in advance, this gives patients a feeling of working together with the healthcare professionals (Gask et al., 2010). When

a care provider shows empathy, this provides a sense of acceptance and understanding (Percival et al., 2016). However, there is a fine balance between giving the patient support and power over their situation and disempowering them (Richards et al., 2006). In our study, the structured CM contacts were initiated through a face-to-face meeting, where each patient could tell his or her own story. This was followed by continuous contacts, enabling a partnership. A partnership with the care provider, taking the entire situation into account, facilitates the establishment of a person-centred approach (Ekman et al., 2011; Starfield, 2011). In our study, patients described that having the possibility to talk about their unique life situation with someone who listened was like having someone who shared their burden and the CM became a "lifebuoy." According to our results, scheduling telephone calls and using a self-assessment instrument, in combination with open patient dialogues, provides an opportunity to build a trusting relationship and seems to empower the patient to self-management. Our study also shows that there is a need to individually adapt the contact for each patient, for example, about the number and timing of telephone calls, for the contact to be empowering. This kind of shift from didactics to encouragement has previously been shown to empower the patient and improve quality of care (Holm & Severinsson, 2014).

Previous studies show that individual support and collaborative care are two factors strongly contributing to recovery for persons with depression, while also being cost-effective (Donohue et al., 2014; Garrison et al., 2016). The patients in our study emphasized the importance of the CM's collaboration, especially with the GP, so that the number of care contacts could be reduced over time. The patients in our study were secure in the knowledge that the CM collaborated with others and would help them get health care when needed. Also, previous studies have shown how important collaborative care management is in supporting recovery for patients with depression (Garrison et al., 2016; Thota et al., 2012). This is also important from a primary care perspective, where access to care (Starfield, 2009) and continuity are vital (Starfield, 2011). In our study, the importance of relational continuity was emphasized, that is, continuity in the contact with someone who is trusted. Relational continuity has previously been described by Haggerty, Roberge, Freeman, and Beaulieu (2013), who emphasized that continuity of care not only means integrating and transferring information in the care process, but also involves a relational aspect. Relational continuity seems especially important among patients with many healthcare contacts (Haggerty et al., 2013). Our study showed that a CM contact contributed to relational continuity. According to our results, using an assessment instrument such as MADRS-S as a basis for further discussion made the patients more involved and active in their own care, which is a crucial aspect of collaborative care (Thota et al., 2012).

### 4.1 | Limitations

The patients were recruited from an intervention study where a CM organization for patients with depression was tested for

the first time in a Swedish primary care context and that involves some limitations. For example, the CMs were new to the role and the method was newly developed and had not previously been tested. Being involved in a scientific study can affect the care process and how care is provided, especially in the beginning of the study. This may have affected the outcome, especially in the first interviews with the CMs' first patients. These interviews were unexpectedly short and did not provide enough information. Perhaps the CMs became more secure in the role after additional patient contacts, explaining why the later interviews became richer. Also, more negative aspects of the CM function might have emerged if focus group discussions had been used, with the participants talking to each other rather than to an interviewer. Another limitation is the minimal ethnic variation in the sample; the results might be different in another population. Also, the fact that this was a research study where the PCC and the CM had access to extended support must be considered, since the usual treatment environment may not be as supportive. However, the CM organization for patients with depression in the PCCs has been broadly implemented after the study was performed and the patients now meet experienced CMs and receive the same support as that offered in the study.

## 4.2 | Implications for practice

This study shows the importance of having a contact person at the PCC who has knowledge of a patient's unique situation. The results suggest that care can be improved for patients with depression through continuity and individualized care with regard to adjustments in treatment, following the patient's trajectory and adapting the number of calls and the duration of the CM contact. However, more studies are needed to further validate these results.

## 5 | CONCLUSION

This is the first time a CM organization for patients with depression has been evaluated in the Swedish primary care context. The results from this study show that a CM organization at the PCC is perceived as supportive by patients with depression. The study highlights the value of a trusting relationship between the patient and a contact person at the PCC, from whom the patient gets support and who can speak for them in the healthcare system, in addition to coordinating care. The continuous contact with a CM also seems to contribute to increased self-management in terms of self-reflection. However, for the contact to be successful, there is a need for flexibility, for example, about number of contacts.

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## RESEARCH ETHICS COMMITTEE APPROVAL

Research Ethics Committee approval was granted by the Regional Committee for Medical Research Ethics in Gothenburg (Dnr 903-13, T403-15, T975-14). All participants were ensured confidentiality and informed that participation in the study was voluntary. All participants signed an informed consent.

## CONFLICT OF INTEREST

None to declare.

## AUTHORS' CONTRIBUTIONS

All authors contributed to development of the design of this study. CU, IS, DH and MJ conducted the interviews. CU and IS conducted the analysis with guidance from ELP. The authors collaboratively wrote the manuscript, and all authors read and approved the final manuscript.

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