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A support nurse may strengthen the participation of patients with low socio-economic status in treatment pathways of head and neck cancer: A theory-based evaluation

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Abstract

Aim: To test and evaluate a support nurse intervention within the head and neck cancer (HNC) pathway.

Background: Even though interventions aiming to support patients with a low socio-economic status have been a focus for development and implementation in several countries, research still shows that these patients often have unmet needs and encounter challenges in communicating with health professionals during their treatment pathways. Furthermore, support interventions are few in Denmark and none of the existing interventions target patients with HNC receiving radiation therapy of whom the majority have a low socio-economic status and therefore potentially carry a high risk of being challenged during their treatment pathways.

Design: A theory-based evaluation was used as framework. A support nurse intervention was designed to offer patients with a low socio-economic status help and support in the initial part of the HNC pathway. Eleven patients were included in the trial period.

Methods: The evaluation of the intervention was based on interviews, a questionnaire survey and field notes.

Results: The expected outputs were achieved, thus: (1) the patients felt supported and assisted, (2) the support nurse was capable of supporting, helping and accompanying the patients, (3) the patients were informed as relevant and understood the information provided. Unexpected outputs were that the support nurse was capable of co-ordinating the pathway in line with the patient's needs and that she facilitated the interaction between patients and health professionals.

Conclusions: Support for patients with a low socio-economic status improves their ability to engage in their cancer treatment pathway. This, in turn, increases their preparedness for participation and, hence, strengthens their choice of treatment.

Reporting method: This study is reported using consolidated guideline for reporting interventions Template for intervention description and replication (TIDieR checklist). We used theory-based evaluation as described by Peter Dahler-Larsen.

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KEYWORDS

head and neck cancer, intervention, patients with low socio-economic status, support nurse, theory-based evaluation

1 | INTRODUCTION

Several studies have indicated that challenges in the encounter with the healthcare system appear more often for patients with a low socio-economic status (SES) than for other patients. This may, among others, show in the challenges this group encounters when communicating with health professionals (Allen et al., 2020; Verlinde et al., 2012) and with navigating the system (Kjeld et al., 2022). Therefore, it has been suggested that the structure of pathways within the healthcare system may negatively influence some patients' encounters with the healthcare system as the structures require patients to take on responsibilty, among others (Jensen, 2021; Kjeld et al., 2022).

Internationally, intervention studies have investigated supporting patients with a low SES, such as patient navigation (Tho & Ang, 2016). These interventions have shown positive results (Budde et al., 2021; Pautasso et al., 2018). The present study concludes our efforts to explore causes that might negatively affect the head and neck cancer (HNC) treatment pathways of patients with a low SES in Eastern Denmark, where we established that the structure of the Danish HNC treatment pathway presents challenges for patients with a low SES (Mondahl et al., 2022, 2023).

2 | BACKGROUND

Internationally, different support initiatives have been implemented over the years (Edney et al., 2022). Nurse navigators have, for example, been used to support disadvantaged patients in their treatment pathways at the hospital, which has produced positive outcomes (Rodrigues et al., 2021). In a systemic review, Ruiz-Perez et al. (2018) however, argued for more navigator interventions targeting cancer patients with a low SES outside the United States. Specifically, the authors argued that the majority of studies testing navigator interventions had targeted patients with breast cancer (Ruiz-Perez et al., 2018), whereas interventions aimed to support other groups of cancer patients were lacking.

In Denmark, navigator roles have been tested only in a few studies that have achieved diverse results while unveiling possible challenges associated with navigator roles. One study involved nurse navigators and targeted gynaecological patients. Thygesen et al. (2013) reported mixed results and found that the nurse navigator was helpful for some patients, but the intervention also had limitations and patients had mixed experiences with their nurse navigator. In addition, the authors argued that patients with a low SES were more likely to benefit from a nurse navigator than patients with a middle or high SES (Thygesen et al., 2013). Another study has tested nurse navigators in a study of vulnerable breast cancer patients. The authors found improved satisfaction and reduced distress among women to whom a support nurse had been assigned (Envold Bidstrup et al., 2016). Both interventions were based on follow-ups with patients after consultations either by phone or through face-to-face encounters. Finally, an ongoing study is testing consultations with nurse navigation, among others, for vulnerable lung cancer patients (Langballe et al., 2022). However, in all three studies, the nurse navigators were not described to accompany the patients at other consultations than the ones scheduled specifically with the nurse navigator. We have previously reported that patients with a low SES were challenged by the information provided during consultations to an extent where the risk of them misunderstanding important information was high (Mondahl et al., 2023), which has also been argued by others internationally (Borrayo et al., 2020; Christensen & Huniche, 2020). Thus, follow-ups on given information may possibly be challenged by misunderstandings of the information that may very well not be clear to the patients. Hence, the patients may be unaware of their need for more information, making it impossible for them to report such a need to a health professional (Mondahl et al., 2023). In 2015, another study led by the Danish Cancer Society aimed to offer vulnerable cancer patients support from a volunteer navigator throughout the patients' treatment pathways. The study showed that patients were satisfied with this extra help and felt safe knowing that the navigator would participate in their consultations. However, the project also revealed some limitations related to the fact that the navigators were volunteers who required training as a navigator within the healthcare system. Furthermore, supervision of the navigators' work and their interaction with the patients was required, among others (Danish Cancer Society, 2015). Internationally, similar challenges associated with incorporating volunteers in interventions within the healthcare system have been identified (Frederiksen et al., 2020; Sundström et al., 2021).

Internationally, navigator and supportive interventions for HNC patients with a low SES have also been tested (Fillion et al., 2009; Kagan et al., 2020). In a Danish context, however, we only identified three larger studies involving navigator roles and targeting vulnerable patients. None of these studies involved patients with HNC, which is the seventh most common type of cancer worldwide (World Cancer Research Fund Internationally, 2022), and which is characterized by affecting a majority of patients with a low SES (Boing et al., 2011; Cohen et al., 2018). A previous study did, however, test a mobile nurse team targeting patients with HNC who needed to undergo surgery. This study reported positive outcomes from the intervention (Mortensen & Nordenhof Mortensen, 2019). However,

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it is important to note that the mobile nurse team did not target patients undergoing radiation therapy, which constitutes a significant portion of the treatment for HNC in Denmark (Danish Health Authority, 2020).

Therefore, we developed the support nurse intervention reported herein. The support nurse intervention targeted HNC patients with a low SES who had shortly before been diagnosed with HNC and who were about to receive radiation therapy.

3 | AIM AND OBJECTIVE

The aim of this study was to test and evaluate a support nurse intervention through a theory-based evaluation addressing how and why the support nurse worked for patients with a low SES in the initial part of the HNC treatment pathway in Eastern Denmark.

TABLE 1 Description of the six steps of theory-based evaluation (Dahler Larsen, 2018).

1. Ask the evaluation question Relates to what the effort can do for the outcome
2. Find data for the programme theory Data can be almost everything
3. Create the programme theory Can be developed as a model or be descriptive
4. Prepare the programme theory for evaluation Ensures that the question of the programme theory may be evaluated
5. Select data-gathering methods Ask the question of what data are needed to complete an evaluation of the intervention
6. Analyse and conclude Analyse and then conclude whether the evaluation weakens or strengthens the belief or hypothesis of the programme theory

4 | METHODS

This study was reported in accordance with consolidated guideline and checklist for and Better reporting of interventions (TIDieR).

4.1 | Theoretical framework

We applied theory-based evaluation using the Peter Dahler-Larsen as a framework for our study. Theory-based evaluation is a process-based approach to conduct evaluation. Dahler-Larsen is inspired by Pawson and Tilley and the theory of 'realistic evaluation', which relates to the critically realistic tradition. The purpose of theory-based evaluation is to identify causality within a single case/situation by investigating *what* works for *whom* and under *what* circumstances. Although Dahler-Larsen is inspired by Pawson and Tilley, he adopts a constructivist approach rather than a critical realistic view whereby the context obtains a decisive role in the intervention (Dahler-Larsen, 2018).

To describe the expected effect of the intervention, a programme theory, in the form of, for example, a logic model (Dahler-Larsen, 2018) must be developed with the aim of describing how and why the intervention is expected to work in the specific context for a specific group of people. In Table 1, we illustrate the structure of theory-based evaluation.

4.2 | Design

According to Dahler-Larsen, the programme theory is developed based on a problem description, which may involve different materials of evidence (Dahler-Larsen, 2018); hence, an understanding must be established of the problem before describing the programme theory. We based the development of the support nurse intervention on findings from our two previous studies in which we investigated which challenges the Danish HNC treatment pathway entailed for patients with a low SES (Mondahl et al., 2022, 2023). In the early phase of development, we performed a literature search on interventions targeting cancer patients with a low SES. The search showed that that navigator interventions would be a feasible approach for our intervention, but because the problem investigated here differs in some important ways from problems explored in previous interventions, we chose to focus on the support nurse rather than a nurse navigator. First, we identified a need for a nurse to accompany the patients during specific consultations in the initial phase of the treatment pathway to help identify and clarify misunderstandings relating to the information given and to support the patient in their communication with the health professionals. Second, we identified a need for the support intervention to be guided by the individual patient's support and care needs rather than conducted in conformity with a set plan. We designed the intervention ensuring that the support nurse would become the contact person from the time of the patient's diagnosis to the transition to the department where their radiation treatment would be provided. The tasks of the support nurse involved contact with the patient immediately after diagnosis to assess and identify any challenges or needs that he or she may have. The support nurse also explored whether the patient had understood information given to him or her about the treatment pathway thereby identifying misunderstandings. The tasks also involved supporting the patients by ensuring that they received help according to their needs; for example, help with practical tasks, navigating the hospitals and coordination of the elements of the pathway.

We acknowledged that the role of the support nurse required specific qualifications within the area of HNC. Thus, the chosen support nurse had several years of experience working with patients with HNC at a bedward, ensuring that the nurse had the necessary specialist knowledge about the patient group and the structure of Danish healthcare. Moreover, the nurse possessed further education in cancer nursing.

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4.3 | Creating the programme theory

According to Dahler-Larsen, a programme theory may be developed as descriptive arguments for how and why the intervention is expected to work or as a logic model that visually shows the elements of the intervention and its expected output. In the process of creating the programme theory, specific evaluation criteria must be selected to structure the evaluation of the effort (Dahler-Larsen, 2018). Hence, the evaluation criteria are defined as outputs that occur if the intervention proceeds as expected. Our assumption was that if each of the three outputs were achieved, the overall outcome would thus be successful, that is that the patients would be prepared before their consultations. In addition, as part of the programme theory, Dahler-Larsen presents the terms 'mechanisms and 'moderator'. Mechanisms depend on the context and are used to explain how the intervention works. Hence, mechanisms leave traces in reality, which are subsequently used to trace the effect of the intervention during evaluation. Furthermore, mechanisms are the means that activate the effect of the effort. Moderators are connected to the mechanisms because they influence how mechanisms work in the given context. Therefore, moderators influence the connection between the effort and the result by showing differences in the context (Dahler-Larsen, 2018). We created our programme theory as a logic model where we applied mechanisms to illustrate how the activities were expected to lead to outputs and produce a certain outcome. In Figure 1 we illustrate the programme theory that underpinned the support nurse intervention.

The moderator box shown in the figure was added to the programme theory after the trial period. Hence, the moderators were identified during the trial period, whereas the remaining parts of the programme theory were developed before the trial period was initiated.

The purpose of the theory-based evaluation is to evaluate whether the evaluation criteria/outputs occur as expected (Dahler-Larsen, 2018), whereby the outcome can be assessed as having been successfully met or not.

4.4 | Recruitment

Eleven patients were included in the intervention. They were recruited immediately after receiving their diagnosis at the outpatient clinic. The inclusion was either performed by the nurse who was present during the consultation or by the support nurse if she was

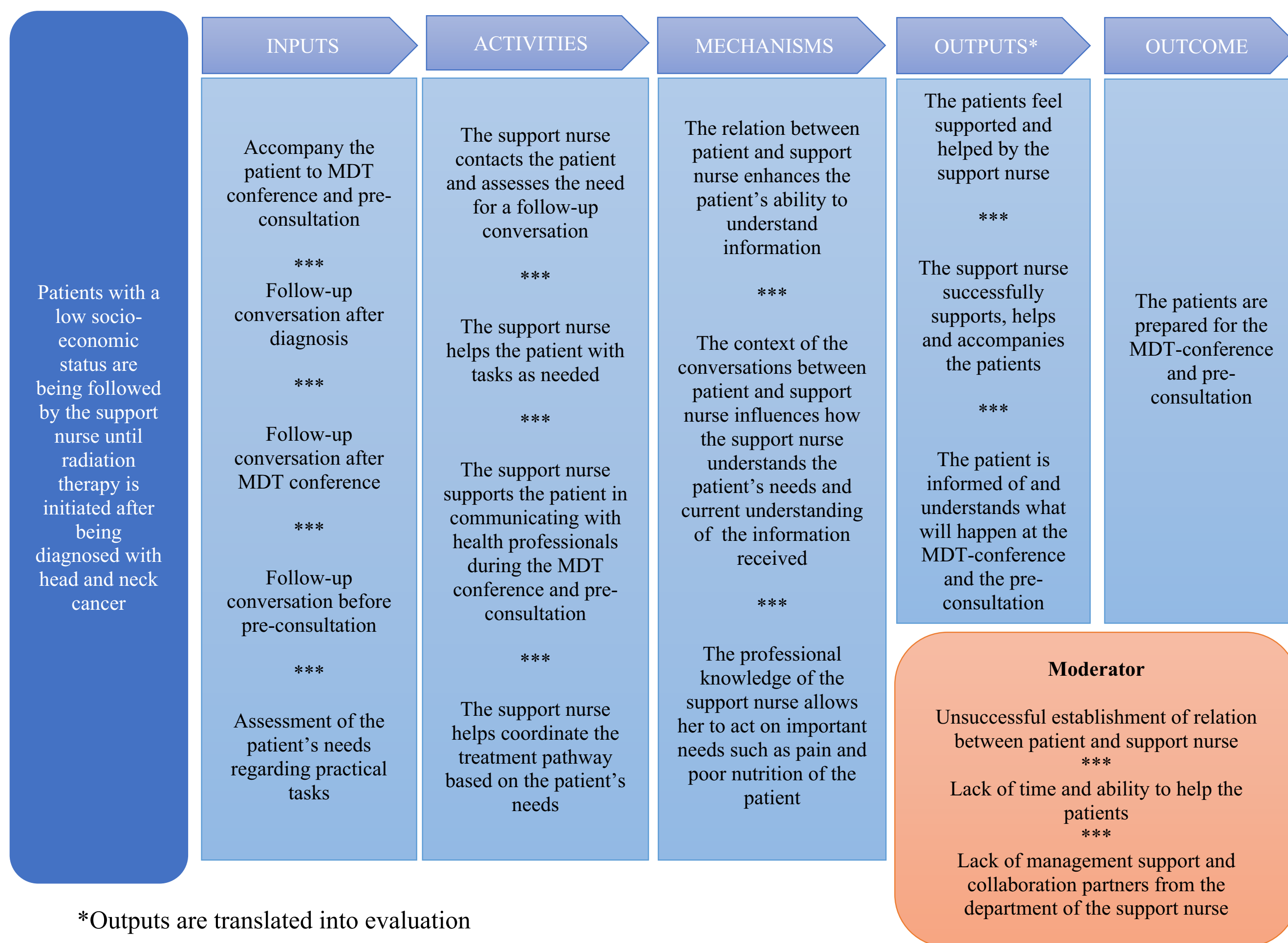

FIGURE 1 The program theory developed for the support nurse intervention.

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present during the consultation. The patients were informed verbally about the project and were invited to participate in the intervention. Table 2 describes the intervention setting and the cancer pathway.

4.5 | Population

The target group included patients diagnosed with HNC who were offered treatment with radiation therapy and/or chemotherapy in Eastern Denmark. We targeted the intervention towards patients with a low SES (Halgren Olsen et al., 2019). Thus, patients included in the intervention needed to meet specific criteria, which are further described in Table 3.

4.6 | Testing and data collection

The intervention trial period ran for 3.5 months from January 2022 to mid-April 2022. The data used in the evaluation included interviews, a questionnaire and field notes.

We used the theory of James Spradley (Spradley, 1979) to conduct patient interviews. The interviews comprised questions to elaborate on the patient's own perspectives of the support and help received from the support nurse. The interviews were conducted by the first author 2–4 weeks after the support nurse intervention concluded contact with the patient. The first two interviews were performed face-to-face; but due to COVID-19, we had to conduct some of the interviews via telephone. As we assessed that this did not influence the responses given by the patients, we then chose to conduct all the remaining interviews by telephone also.

The questionnaire survey was based on nine questions in which we aimed to evaluate the patients' satisfaction and experiences (see Data S1). The questions were worded in easily understandable Danish, but they were not validated. We pilot tested the questionnaire with the first two patients to ensure that the questions were easy to read and understand. The first author delivered the questionnaire survey to the first two patients who were encouraged to ask for help if they were in doubt about the meaning of the questions. The patients had no doubts relating to the questions. We therefore chose to let the support nurse or a nurse at the outpatient clinic deliver the questionnaire survey to the rest of the patients. We used a Likert scale in some of the questions and a visual analogue scale (Pronovost et al., 2016) for other questions. Providing the response options as a Likert scale enabled us to receive verbal descriptions of the effect of the support nurse, whereas the VAS gave the patients the opportunity to graduate their responses (Voutilainen et al., 2015).

The patients were informed verbally about their anonymity and possibility to withdraw their participation. After the questionnaire survey had been completed, it was placed in an envelope, and the answers were analysed once all patients had given their answers. This procedure was introduced to further ensure that the patients could not be identified. Nine of the eleven patients answered the questionnaire survey. One patient died before radiation treatment was initiated, and another patient experienced a drastic deterioration of his condition, which is why we chose to exclude this patient from the questionnaire survey.

Lastly, we included data from field notes made by the support nurse. The field notes were transcripts of the meetings and conversations between the support nurse and the patients.

In the analysis and evaluation phases, we combined all data.

TABLE 2 Description of the treatment pathway of the head and neck cancer pathway in Eastern Denmark (Danish Health Authority, 2020).

The first consultation at the hospital
The first consultation is held at Zealand University Hospital, Koege.
The patient is examined, and biopsies are taken on the same day or during surgery at a scheduled time on another day. The patient is diagnosed.
Multidisciplinary team (MDT) conference
The MDT conference is held after the diagnosis has been made at Rigshospitalet.
Present at the MDT conference are two head and neck surgeons (one from each department), an oncologist and a nurse.
The consultation consists of an examination of the patient and dissemination of information about the treatment that the patient is offered.
The first consultation at the treating department
Immediately after the MDT conference, the pre-consultation is held at Naestved Hospital where the patient receives radiation therapy and chemotherapy.
The pre-consultation is attended by an oncologist and a nurse, and the purpose is for the patient to learn about the treatment and the side effects that are associated with the specific treatment.

4.7 | Data analysis and evaluation

We combined the analysis of process and effect as described by Dahler-Larsen. In the Results section, we therefore present the analysis of the process evolving between input and output, which implies an analysis of the connection between input, activities, mechanisms and outputs (see Figure 1).

In the initial phase, we analysed each data set (questionnaire survey, interviews and field notes) separately, focussing on each of the three evaluation criteria (Outputs—see Figure 1).

We analysed the questionnaire survey according to the way in which data were obtained. Hence, VAS data were analysed by median and range, and Likert data were analysed numerically, as shown in Table 4.

In the analysis of the interviews and field notes, we focussed on establishing *what* works for *whom*, *why* and *under what circumstances* (Dahler-Larsen, 2018) by exploring how the activities of the support nurse intervention were transformed (process) into

TABLE 3 Description of the patients and the low socio-economic status criteria.

Patients	Low income	Short education (under 10 years)	Occupational status (not working: Retirement, cash benefits, early retirement, etc.)	Area of residence (outside the bigger cities)	Few relatives/ small network	Lifestyle (consuming alcohol and cigarettes)
Patient 1		X		X	X	X
Patient 2	X	X	X	X	X	X
Patient 3	X	X	X	X	X	X
Patient 4	X	X	X	X	X	X
Patient 5	X	X	X	X	X	X
Patient 6	X	X	X	X	X	X
Patient 7	X	X		X		X
Patient 8	X	X		X	X	X
Patient 9		X	X	X	X	X
Patient 10	X	X	X		X	X
Patient 11	X	X	X	X	X	X

the expected evaluation criteria (outputs). Hence, our purpose was to explore *how* and *why* mechanisms produced certain outputs of activities occurring *between the support nurse and the patient* in the specific *context*. We also identified how certain moderators would influence the connection between the input and the effect in specific contexts.

4.8 | Ethical considerations

The study was conducted in accordance with the Helsinki Declaration (World Medical Association, 2020) and as approved by the Regional Research Ethics Committee (17–000048) and the Regional Data Protection Agency (REG-111-2019).

Patients were informed about the intervention verbally and in writing, and all patients were asked to fill out a declaration of consent before their final inclusion in the project. In addition, department staffs were informed in detail about the study and the intervention.

5 | RESULTS

We used the three evaluation criteria (outputs) to structure the analysis. Below, we present the analysis of the process structured by three subheadings: (1) The patients feel supported and helped by the support nurse. (2) The support nurse is able to support, help and accompany the patients. (3) The patient is informed of and understands what will occur at the MDT conference and at the pre-consultation. In Table 4, we present the findings from the questionnaire.

5.1 | The participants feel supported and helped by the support nurse

In the questionnaire survey, we initially asked the patients how satisfied they were with the support nurse intervention (see Table 4). We found a median score of 10 showing that most patients were very satisfied with the support nurse. This was also expressed by the patients in the interviews and in the encounter with the support nurse herself.

> I am already really pleased with you, and I think that everything will be much easier now (Quote from the field notes of the support nurse about Patient 9)

As the patients felt supported and helped, a relation between the patient and the support nurse developed. This was a mechanism that actively affected the outcome. The patients' connection to the support nurse early in the pathway increased their trust in her because they knew her better than they knew any of the other health professionals.

> It is good that I now have your number because now I can always call you instead of calling places where no one knows who I am or how I am feeling, or does not know who the hell I even am. The other system is difficult, and they do not know me like you do (Quote from the field notes of the support nurse about Patient 1)

The patients often called the support nurse several times after their first meeting. The phone calls were based on the patients' need for help with practical tasks such as obtaining a parking permission or figuring out how to find their way around the hospitals, but the calls were also rooted in patients' feeling confused or frustrated about the pathway. In the interviews, the patients explained that they found it was much easier to call the support nurse because they knew who she was and vice versa. Several patients expressed doubt about calling one of the departments because they did not know who to call or who they would eventually end up talking with. In the questionnaire survey, we asked if the patients had experienced that it was difficult to contact the support nurse. As shown in Table 4, most patients answered that they did not find it difficult at all to contact the support

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TABLE 4 Data from questions answered in by VAS in the questionnaire survey.

Question	Median	Range
On a scale from 0 to 10 where 0 is 'not at all satisfied' and 10 is 'very satisfied', how satisfied were you with your connection with the support nurse?	10	7–10
On a scale from 0 to 10 where 0 is 'not important at all' and 10 is 'very important', how important was it for you to talk to the support nurse?	10	7–10
On a scale from 0 to 10 where 0 is 'very difficult' and 10 is 'not difficult at all', how difficult was it for you to contact the support nurse if you needed it?	10	5–10
On a scale from 0 to 10 where 0 is 'no influence at all' and 10 is 'really large influence', which influence did the support nurse have for your experience of losing sight of your treatment pathway?	10	9–10

nurse. One patient did, however, score this question 5, which may indicate that some patients still struggled to contact the support nurse as needed.

In addition, the patients expressed that they felt safe knowing that the support nurse would always help them with their needs and accompany them during consultations where they feared becoming confused about the information provided. We asked the patients how they felt about being associated with the support nurse and gave them a Likert scale to provide their response. All patients answered that being associated with the support nurse and having her by their side during consultations made them feel safe. However, in the free-text field provided at the end of the questionnaire survey, one patient did describe a hope of having been associated with support nurse for a longer period of time.

> It meant a lot (the presence of the support nurse) and it was an anxiety reliever, but I would, however, have liked the support to continue for a longer period of time. In the last part of the treatment pathway there was no support. (Quote from the questionnaire)

In the analysis of the field notes, we identified that every patient expressed being confused about the information they had received and also in doubt as to what issues the consultations would address. Thus, the support nurse's presence afforded the patients an opportunity to follow-up on the information after their consultation. This also allowed them to feel safe and be more relaxed during the consultations.

The framework of the contacts between the support nurse and the patients was informal meetings; thus, the context of their conversations was very different from the consultations because attending consultations would also involve that the support nurse followed the patient for blood testing or that they sat in the waiting room together. The support nurse's role provided unique advantages in identifying and acting on the patient's needs. The encounters with the support nurse differed from the other consultations at the outpatient clinic in terms of their unscheduled and unstructured nature. Unlike the appointed treatments, these meetings involved no predetermined agenda. Instead, the support nurse engaged with the patients about their pathways, creating a different context for their interaction. This context played an active role in facilitating effective communication and support.

5.2 | The support nurse is able to support, help and accompany the patients

The mechanism of the relation between the patient and the support nurse was important because it influenced how and the extent to which she was able to support and help the patient. The relation established between them meant that the patients trusted the support nurse's ability to help, why they would contact her with their every need. This was expressed by the patients during the interviews.

> "She (the support nurse) just went in and took care of it all (…) it took her like 10 minutes and then she called back to say that it was fixed (…) she was really effective" (Interview with Patient 2)

In addition, the relation allowed the support nurse to obtain information about the patient that might not otherwise have been passed on to any other health professional. This information allowed her to understand the basis of the patient's understanding of the information given at the MDT conference and during the pre-consultation, which was necessary for her to act on any misunderstandings or confusions.

> The nurse informs the patient about hair removal before the operation, which he has to do at home. The patient nods his head. I know that the patient only uses a shaver and not a razor, so therefore I interrupted the nurse and asked her whether it had to be done with a razor to which she replied yes (field notes from the support nurse about Patient 8)

The support nurse's knowledge about the patient also allowed her to identify when the patient was confused or challenged by some of the practical tasks that he or she needed to handle themselves during the treatment pathway. Some patients articulated a need for help exclusively to the support nurse, whereas for others the support nurse offered her assistance when she discovered that the patient was challenged by some issue.

> The patient asks the nurse about transport and the nurse explains that this is something that the patients need to handle themselves. The patient looks at me and

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> says: But I am not used to doing that, can you please help me? (field notes of the support nurse about Patient 8)

For the support nurse to help and support the patients, the context needed to allow her to act on the patients' need. When the support nurse was attending several patients at the same time, she struggled to prioritize her patients' various needs for help and assistance. The active mechanism was, however, that the support nurse possessed the necessary professional competencies to identify and then act on any specific needs for help.

> The patient calls me a few days after the PET scan. He had had a bad experience with the mask and therefore had some questions about it. I explained that it is possible for him to have some soothing medication before the radiation therapy. The patient tells me that he is very happy about that information and asks me if I can call the nurses (at the department), and let them know because he otherwise will just forget to mention it himself. We agree that I should call the department after our conversation. (Field notes of the support nurse about Patient 11)

The support nurse's knowledge about the patient and the treatment pathway allowed her to help the patients with practical tasks. Furthermore, her specialist knowledge about patients with HNC allowed her to act on needs that the patients had not necessarily articulated themselves but which she had identified needed to be resolved to increase the patient's well-being and ensure that they were ready for their treatment.

> I interrupted the conversation about planning of radiation therapy because I knew that the patient was in less pain during the morning, therefore I suggested that the treatments should be given as early as possible. (Field notes of the support nurse about Patient 5)

In addition to the above elements, we found that the different collaboration partners of the support nurse constituted an important contextual factor. The collaboration partners were important for the support nurse because she often faced questions about the pathway, needed to co-ordinate appointments or required help with patient prescriptions. Thus, a lack of available collaboration partners was a moderator influencing the connection between the inputs and the outputs by impeding her ability to act on the patients' needs.

5.3 | The patient is informed of and understands what will occur at the MDT conference and during the pre-consultation

In the questionnaire survey, we asked the patients how the support nurse had affected their understanding of the treatment pathway. Six patients answered that she had a 'very large influence' and three answered that she had 'large influence'. In addition, we asked the patients how important the support nurse was to their experience of having an overview of the treatment pathway. All patients experienced that the support nurse had a very large influence on their general understanding of the treatment pathway. In the interviews, the patients also articulated that the support nurse influenced their understanding and overview of the pathway because she was able to inform them before and after the consultations, giving them better conditions for remembering and understanding the purpose of the consultations and keeping track of the information they had been given.

> "It was a safety… And yes, we talked about if I had any special appointments to remember and that book and so on. She explained to me what was important now and what could wait a bit. That was a really big help" (Interview with Patient 3).

> It meant everything for my understanding (Answer from questionnaire).

> The doctor asks the patient how much he knows about the treatment. The patient answers: I have talked to the support nurse about it, and I know that I need to have a mask made for me and that it is usually about 33-34 times of radiation therapy. And we also talked a bit about the side effects (Field notes of the support nurse about Patient 8).

The nurse's conversations with the patient provided the context allowing the support nurse to follow-up on the patient's misunderstandings or confusion and afforded her the opportunity to inform the patients again, but in another setting and with smaller doses of information than they received during the consultations. This allowed the patients to focus on what was important to remember and understand at the present time rather than focussing on other consultations or being confused about future appointments. Thus, unlike the traditional framework, the framework of the support nurse intervention implied that she was present before, during and after the consultations, which the current contextual circumstances rarely allowed. Given the involvement of three different departments in the initial phase of the treatment pathway, it is common for patients to have scheduled consultations with unknown health professionals at the departments. The presence of the support nurse was the active mechanism allowing the patients to be more relaxed, knowing that she was there to explain what would happen before the consultation and to assist with follow-up after the consultation.

> She helped explain what the doctors said, and she asked them how I should understand what they said. Help I would not be without under any circumstances. It gave me the necessary help to be more relaxed (Answer from questionnaire).

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Because the support nurse was able to inform the patients more specifically and as the event occurred, the <they> only needed to focus on information about their upcoming consultation, which allowed them to understand and remember what would happen. This was expressed by the several patients during interviews.

> "Yes, I felt like I was prepared. I was not nervous about anything... I think I would have been nervous otherwise because I simply did not know what it was all about" (Interview with Patient 1).

> "She explained to me what would happen and so on. I was unsure about everything" (Interview with Patient 6).

In the field notes, we identified several situations in which more than half of the patients stated during the consultations that they were already familiar with the information given by the health professionals because the support nurse had already let them know what would happen, underscoring that the support nurse enhanced the patients' understanding of the care provided.

5.4 | Other outputs

We found that the role of the support nurse was important for co-ordination of the patients' pathways because she served as a link between the three departments and was the healthcare professional who knew the patients the best because she had followed them from the time of their diagnosis; hence, the output was a co-ordinated pathway based on the patients' needs. The active mechanisms involved in co-ordinating the patient's pathway were maintaining an overview of the pathway and possessing knowledge about the patient, a combination which was unique for the support nurse due to the fragmentation of the pathway.

> The patient had a low haemoglobin level and needed a blood transfusion. The patient struggled to see the need for this and therefore became angry with the doctor when he explained that the patient needed to have the blood transfusion at another hospital (a fourth hospital). When I asked the patient about his reaction, he explained that he could not face having to drive the long distances for many consecutive days. I therefore checked if it would be possible for him to receive the blood transfusion in his local health centre. Luckily, he could. This meant that the patient did not need to drive the long distance and he therefore accepted the blood transfusion. (Field notes of the support nurse about Patient 6)

We also established that the presence of the support nurse during the consultations meant that she had an influence on the interaction between the patient and the health professionals. Thus, she was able to help and support the patient in his or her communication with the health professionals, and to explain on behalf of the patient if she identified that some issue required elaboration. We interpret that the active mechanism that led the activities of the support nurse to this output was her professional specialist competencies. These competencies meant that she understood the pathway and knew what the health professionals needed to know about the patient to optimize the treatment pathway; hence, she voiced patients' concerns while also assisting the health professionals.

6 | DISCUSSION

To our knowledge, this is the first study to test a support nurse intervention targeting HNC patients with a low SES in Denmark. The overall result of the support nurse intervention was that the outputs of the programme theory occurred during the trial period. The patients felt supported and helped by the support nurse, the support nurse succeeded in helping and supporting the patients meeting their needs, and the patients were informed as relevant and understood what would occur at the two consultations.

We found that the relation between the support nurse and the patient was vital to establishing trust and acquiring relevant knowledge about the patient, thereby facilitating the patient's care pathway. Because the patients trusted the support nurse, she was able to obtain relevant and important information and pass that information on to other healthcare professionals. This is important as we have previously shown that patients who experience not understanding what is communicated to them withhold important information, which has a negative bearing on their participation and, eventually, their treatment choices (Mondahl et al., 2023). Thygesen et al. (2013) also found that trust was an essential component in the relation between the nurse navigator and patients (Thygesen et al., 2013). We found that the patients felt safe while being supported and accompanied by the support nurse, which we suggest were the mechanisms allowing an expedient relation to evolve between them. This is in line with the findings by Nguyen et al. (2019) who found that patients with high levels of anxiety and a low educational level had a higher risk of not being able to remember information in the initial phase of fast-track cancer treatment (Nguyen et al., 2019). Furthermore, we have previously found that the patients were challenged by the contents of the information and by having to remember the information given to them (Mondahl et al., 2023). We therefore argue that the support nurse intervention may be a solution for patients who are challenged by information overload because they feel safe knowing that they have the support nurse by their side. This issue was mentioned by several participants in the interviews and in the questionnaire survey. We therefore suggest that the patients' level of anxiety may likely be reduced if they are accompanied by a support nurse.

In addition, results from an integrated review showed that nurse navigators increased trust not only between the nurse and the patient but also between the patient and the other health professionals, which had a considerable impact on the continuum of care and

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the communication process during the treatment pathway (Pautasso et al., 2018). Likewise, Dencker et al. (2021) found that patients who were accompanied during cancer consultations were more likely to communicate well with the health professionals (Dencker et al., 2021). Similarly, we found that the interaction between patients and health professionals was influenced by the support nurse's presence during the consultations as she was able to act as the communication link between the patient and the health professionals. This further means that the time spent on each patient may potentially be reduced during consultations because the support nurse may conduct follow-up conversations with the patients, which was articulated as a safety by the patients and the involved health professionals alike.

In the development phase, we assumed that the role of the support nurse needed to be filled by a nurse with specialist knowledge. We assumed that such a nurse would be able to navigate the pathway as well as various departments, and that she would be able to identify and act on any needs patients encountered. However, previous studies have indicated that volunteers may be used in interventions to support and help patients (Sundström et al., 2021); but volunteers' education, training and knowledge about the healthcare system have been identified as challenges in such interventions (Frederiksen et al., 2020) along with difficulties on the part of the volunteer to identify professional boundaries (Phillips et al., 2014). Therefore, we argue that the support person role is best handled by a nurse. In addition, in line with others (Kjeld et al., 2022), we have previously argued that the organizational structures of the healthcare system may have a negative influence on pathways for some patients due to expectations of participation, among others (Mondahl et al., 2022). It is also shown that HNC patients with a low SES are challenged by such expectations to an extent where their abilities to engage in their own pathway, in addition to making informed decisions, were influenced negatively (Mondahl et al., 2023).

We therefore raise the important question whether the best solution to this problem is to involve non-professionals as primary support persons for patients with a low SES in a complex cancer treatment pathway. Indeed, we argue it is not.

The combination of a healthcare professional's, in this case a support nurse's, ability to identify and act on patients' needs, the patients' trust in the support she provided and the setting of their encounters allowed the patients to receive important support tailored to their specific, individual needs, reduced misunderstandings and mitigated communicative challenges with other health professionals. The follow-up conversations meant that the support nurse was able to correct any misunderstandings about the treatment, thus ensuring that the patient would be correctly informed about any upcoming consultations. In addition, she was able to interfere during the consultations if she believed that the patient was confused or at risk of misunderstanding the information provided. The support nurse's ability to structure her support and assistance according to each patient's needs, free from the timetable set by the pathway framework, was a key contextual factor and mechanism enabling the effect of the intervention. Additionally, the unscheduled nature of the support nurse's work and meetings with patients was an important contextual circumstance. This allowed the support nurse to meet the patients on other terms than those that applied for other health professionals during the planned consultations, which were often structured by an agenda.

The organization of cancer pathways often involve several consultations and controls at outpatient clinics, which implies that encounters between patients and health professionals are pre-scheduled and structured according to the purpose of the consultation; hence, even though these consultations might be scheduled in order to identify problems and involve the patients, this purpose may neither be clear nor be achievable for all patients. We therefore suggest that the enabling contextual factor for the effect of the support nurse was the creation of conditions that facilitated patient interaction with a health professional, specifically the support nurse. We further argue that these conditions encouraged patients to take action when needed because they knew that they had access to the support nurse whenever needed.

Thus, based on the fulfilment of the three outputs, we argue that the patients were successfully prepared for the MDT conference and the pre-consultations because they received the support they needed to participate in their treatment pathway. We further argue that preparing and supporting patients during these consultations strengthens their ability to make treatment decisions. Finally, we hypothesise that optimal support from a support nurse may help address documented social inequalities in the cancer pathways for patients with a low SES who face challenges during their HNC treatment. However, further research is needed to compare the effect of the support nurse between different groups of patients.

6.1 | Strength and limitations

When conducting theory-based evaluation, a problem description guides the development of the corresponding programme theory. Thus, the development of the intervention occurs after the problem description has been made, which may be argued to be a limitation because the problem description then cannot serve as 'the before picture' because the intervention had not yet been developed. Hence, if we had instead chosen to compare a before and an after situation, we could have made more specific investigations of the treatment pathway based on the design of the intervention in order to learn what to search for and compare. In addition, the trial period did not include comparison of two participant groups; hence, Dahler-Larsen (2018) states that causality may be found within a single case (Dahler-Larsen, 2018). Even so, within the tradition of positivism, this would be considered a limitation of this study. We argue, in line with Dahler-Larsen (2018), that theory-based evaluation is rooted within the tradition of social constructionism (Dahler-Larsen, 2018); thus, the context plays a large role because it is considered to be constructed between the actors within. Based on this view on the world, a comparison of a before and an after, or between two groups, may always be questioned because the context would not necessarily be the same. We acknowledge the strength of combining qualitative and

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quantitative data from the patients, despite the limitation of the non-validated questionnaire survey. We also acknowledge that our study included only men, which may potentially have influenced the results. However, we argue that this reflects the two to four fold higher incidence of HNC in men than in women (Gormley et al., 2022). Furthermore, we recognize the consideration of excluding patients with middle or higher SES from support, even if some of them may also need it. However, this decision aligns with the focus of the larger study on addressing challenges during head and neck treatment specifically for patients with a low SES.

Additionally, we address the fact that we structured our literature search to interventions targeting cancer patients. This may have excluded relevant interventions targeting other patients with a low SES. Finally, we acknowledge that a larger sample size would have increased the trustworthiness of our evaluation of the intervention.

7 | CONCLUSION

Overall, the support nurse intervention was implemented and tested as expected and described in the programme theory and all three evaluation criteria (outputs) were met—this is the reason for the original programme theory being confirmed in practice. Overall, the support and help provided by the support nurse allowed the patients to receive the help they needed to comply with the treatment pathway in regard to their own needs, including any need for extra and targeted information, which conclusively prepared them for the MDT conference and the pre-consultation.

We argue that collaboration with other health professionals may constitute moderators of the support nurse intervention if clear agreements have not been made about the support nurse's access to help and assistance at the involved departments.

Conclusively, we argue that within the HNC pathway in Eastern Denmark, the support nurse intervention was successful in the pathways of low SES patients, and we suggest that these findings are transferable to similar settings, that is, other cancer pathways providing different therapies to other patient groups with a low SES.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

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DATA AVAILABILITY STATEMENT

Some data will be available on request.

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