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The views of healthcare professionals on self-management of patients with advanced cancer: An interview study

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ABSTRACT

Objectives: Self-management of patients with advanced cancer is challenging. Although healthcare professionals may play a crucial role in supporting these patients, scant scientific attention has been paid to their perspectives. Therefore, we examined healthcare professionals' views on self-management and self-management support in this population.
Methods: We conducted qualitative interviews with 27 purposively sampled medical specialists (n = 6), nurse specialists (n = 6), general practitioners (n = 8) and homecare/ hospice nurses (n = 7) in the Netherlands. Transcripts were analysed using thematic analysis.
Results: Healthcare professionals experienced self-management of patients with advanced cancer to be diverse, dynamic and challenging. They adopted instructive, collaborative and advisory roles in self-management support for this population. Whereas some professionals preferred or inclined towards one role, others indicated to switch roles, depending on the situation.
Conclusions: Just like patients with advanced cancer, healthcare professionals differ in their views and approaches regarding self-management and self-management support in this population. Therefore, instructive, collaborative and advisory self-management support roles will all be useful under certain circumstances.
Practice implications: Healthcare professionals can support self-management by being aware of their own views and communicating these clearly to their patients and colleagues. Education in self-management support should include self-reflection skills and discuss the relation between self-management and professional care.

1. Introduction

In the past decades, there has been a paradigm shift from paternalistic towards more participatory, patient-centred healthcare [1–3]. This shift was fuelled by broader societal developments. In the Netherlands, for instance, there has been a gradual shift from a welfare state into a "participation society", where individual well-being is no longer primarily a state responsibility and people should create their own support and safety nets [4]. Consequently, patients are expected to take a more active role in their health and care. Together with the growing prevalence of chronic diseases and the subsequent need for patients to integrate illness into their daily lives [3,5], these developments have drawn the attention to self-management. In the context of disease, self-management is commonly defined as 'the strategies used by persons to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with the disease' [6]. As such,

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self-management refers to a comprehensive and interactive process that is not limited to medical management, but also includes daily life management and emotional or identity management [7–9].

The concept of self-management was developed and has mainly been used within the field of chronic diseases. However, also for patients with advanced diseases, such as advanced cancer, self-management concerns a major issue: their disease consequences can be heavily fluctuating and disruptive, involving (invasive) treatment regimens [10], increasingly disabling symptoms [11,12], and social and existential implications of altered normality and impending death [13,14]. Moreover, as medical and technological advances have increased the average life expectancy of patients with advanced cancer, they generally need to manage these consequences during more protracted, yet uncertain illness and end-of-life trajectories [15]. A recent systematic review showed that their self-management strategies are highly personal, varying from self-administering medications to joining peer support groups [16]. Additionally, these strategies include specific behaviours to manage the end of life, such as sorting out financial affairs and making funeral preparations [16–18]. Furthermore, within each self-management domain, strategies are divergent, ranging for instance from coordinating care to fully delegating it to others [16]. The accounts of patients with advanced cancer have revealed that adopting and combining strategies can be highly challenging and is pervaded by ambivalence and changing or competing priorities, for example when prescribed medications are experienced to threaten usual daily routine [10,14,16,19,20].

Ineluctably, self-management of patients with advanced cancer also requires efforts from their healthcare professionals, who need to relate and respond to the large diversity of self-management strategies they encounter. They may be confronted with patients who request or refrain from shared decision-making [16,21,22], request access to their medical records [23] or start practising complementary and alternative medicine [16]. Besides relating and responding to such strategies, healthcare professionals have the opportunity to support patients in their self-management. Nevertheless, studies to date have mainly addressed patient perspectives. The few studies that did assess professional perspectives focused on nurses [24–29], who are traditionally most closely involved with patients' daily lives, connect the multiple aspects of advanced cancer care, and have therefore been assigned a key role in self-management support [30,31]. Yet, other healthcare professionals, such as medical specialists and general practitioners, need to deal with and support self-management as well. Examining professional views from a broader perspective will enhance our understanding of self-management and self-management support in patients with advanced cancer, and might identify potential targets for improving self-management support. Therefore, we aimed to answer the following research questions:

1. What are healthcare professionals' experiences, attitudes and challenges regarding self-management of patients with advanced cancer?
2. How do they view their own roles in self-management support for patients with advanced cancer?

2. Methods

2.1. Study design and sample

We conducted a qualitative semi-structured interview study among medical specialists, nurse specialists, general practitioners and nurses who are involved in care for patients with advanced cancer. These healthcare professionals were recruited purposively via the clinical network of the research group and through the snowball method, thus ensuring variation in characteristics of healthcare professionals (e.g. age, profession, work setting) as well as their patient populations (e.g. cancer type). To ensure that diverse views were covered, we explicitly asked participants if they knew colleagues who might have different experiences or attitudes than they had themselves. Also, a multistage sampling approach was adopted, directing recruitment more specifically at professionals working in particular settings (e.g. a socio-economically deprived neighbourhood) and fields of expertise (e.g. palliative care, experimental clinical trials) as data collection proceeded [32]. Healthcare professionals were invited to participate in the study via email. Those who were interested were contacted again by phone or email to provide them with additional study information and schedule an interview appointment.

Box 1
Interview guide for semi-structured interviews among healthcare professionals.

What does self-management mean when it concerns patients with advanced cancer?
- What are your associations and connotations?
- Introduction of self-management definition: 'the strategies used by persons with the aim of managing the physical, psychosocial and existential consequences of living with advanced cancer and its treatment' [33].

What do patients with advanced cancer do to manage the consequences of their disease?
- What do they generally not do themselves? Are there tasks they mainly leave to you or other healthcare professionals?

Do patients with advanced cancer differ in their self-management? If so, how do they differ from each other?
- Do they differ in their self-management behaviours? Or in their self-management preferences and skills?

What factors complicate or facilitate self-management of patients with advanced cancer?
- E.g. characteristics of patients, their informal caregivers or professional care?

Has self-management of patients with advanced cancer changed over the past years, and, if so, how has it changed?
How do you experience these changes?

How does self-management of patients with advanced cancer affect you and your work?
- Does it for example influence your professional activities, responsibilities or workload?

What is your impression of the consequences of self-management for patients themselves?
- When do you think self-management has succeeded?

What are your ideas about self-management support for patients with advanced cancer?
- How do you see your own role in self-management support for these patients?

2.2. Measurements and data collection

Prior to the interviews, a semi-structured interview guide was developed (see Box 1). This interview guide was tested with two colleagues who have clinical work experience and were not otherwise involved in the study. To allow for differences in concept, but also ensure validity and comparability of interview data, we first inquired for participants' views on the definition and meaning of self-management among patients with advanced cancer, and, subsequently, proposed a broad and commonly used self-management definition, which had been adapted to the context of advanced cancer [33]. Interviews were administered between March 2018 and July 2018 by three researchers (SD, RS, JR). Healthcare professionals were interviewed face-to-face (mean duration: 1 h) at a location of their choice, which generally was their work setting. All interviews were audio recorded. At the beginning of each interview, participants provided verbal informed consent. After the interview, they completed a short survey on sociodemographic characteristics. All interviews were transcribed verbatim and anonymised.

2.3. Data analysis

Interview data were inductively analysed following the principles of thematic analysis, using open coding [34,35]. Transcripts were read thoroughly and multiple times to get familiar with the data. Initial codes were assigned and collated into potential themes. Emergent themes were subsequently reviewed, redefined and described in relation with the coded extracts [34]. A sample of 10 transcripts were coded by two researchers (SD, RS) independently. The analysis of the remaining transcripts was performed by one researcher (SD) and checked by another (RS). Codes, themes, their interpretations and the clustering of quotes were regularly discussed within the project team. Through constant comparative analysis, experiences, attitudes and challenges regarding patient self-management as well as professional self-management support roles were compared both within and between participants [35]. Data on healthcare professionals' roles in self-management support for patients with advanced cancer were classified based on their statements about a) the degree of initiative and control participants reported to take in supporting self-management (i.e. self-management support style) and b) the scope of the self-management support activities they described (i.e. the content of self-management support). Sociodemographic characteristics were summarised using descriptive statistics.

Table 1
Background characteristics of healthcare professionals included (n = 27).

Characteristic	n (%) Mean (SD); [min – max][a]
Age in years	50 (11); [30–64]
Sex	
Male	7 (26)
Female	20 (74)
Profession	
General practitioner	8 (30)
(Trainee) Medical specialist (oncology, internal medicine, otolaryngology, head and neck surgery, pulmonology)	6 (22)
Nurse	7 (26)
Nurse specialist	6 (22)
Work setting	
General practice	8 (30)
Academic hospital	9 (33)
General hospital	3 (11)
Home care	5 (19)
Hospice care	2 (7)
Years of working experience	22 (12); [2–39]

Abbreviations: n = number; SD = standard deviation; min = minimum; max = maximum.
[a] Categorical characteristics presented as n (%); Continuous characteristics presented as mean (SD); [min – max].

3. Results

3.1. Study population

Of the 33 healthcare professionals who were approached, 27 eventually participated. Four professionals did not respond to the invitation emails and reminders, and two refused to participate because of a lack of time. The participating 27 healthcare professionals (74% female; mean (SD) age: 50 (11) years) worked as a general practitioner (n = 8), medical specialist (n = 6), nurse (n = 7) or nurse specialist (n = 6) in the hospital, home or hospice setting in various regions of the Netherlands (see Table 1).

3.2. Experiences with self-management of patients with advanced cancer

Healthcare professionals associated self-management of patients with advanced cancer with choices and behaviours in various domains. Some of them described it primarily in clinical terms, focusing on strategies related to disease management and medical care, such as complying with treatment regimens, monitoring symptoms and navigating the healthcare system. Others adopted a broader perspective, addressing choices and behaviours regarding life in general, including domains of social support and existential wellbeing. According to some professionals, patients' strategies were not always compatible with their professional care. For example, when patients adopted stringent diets while chemotherapy required increased energy intake, or when patients deliberately withheld information about their symptoms for fear that professionals would decide to discontinue their treatment. Without exception, professionals mentioned the use of alternative medicine among a considerable proportion of their patients with advanced cancer, including strategies that could alter the safety or effectiveness of regular therapies. Some of them discussed their experiences with patients who substituted regular care with alternative care strategies:

> *'I have encountered patients who decided to quit medical treatment because their faith healer had told them their cancer was gone.' – HCP02, medical specialist*

Participants experienced large differences in self-management between patients with advanced cancer, describing a variety of different patient roles. On the one hand, they provided examples of patients showing proactive behaviours, and, on the other hand, they distinguished patients who adopt more passive or even avoidant approaches in their presence:

> *'Some patients are very determined. Patients who have mapped out a detailed route for their disease trajectories and might go very far to realise the intended route, by searching and reading scientific literature themselves, networking and approaching people, arranging second opinions and things like that. Other patients are much more passive, just like "Doctor, or nurse, whatever you say, that is how we are going to do it".' – HCP07, medical specialist*

Healthcare professionals shared the experience that recent healthcare and broader societal developments have urged patients to be more proactive in their self-management. They described the implementation of online patient portals that contained increasing amounts of medical correspondence and sometimes even disclosed clinical test results before these had been discussed between patient and professional. They also spoke about the emergence of a 'self-management industry', in which business people try to advertise

their self-management support programmes within medical settings:

'I receive emails saying "We know you work at the oncology clinic, I have written a book about breast cancer and would like to bring it to your attention, can I come visit?" […] Coaches who visit the hospital and ask me whether they may distribute some leaflets here (shows a brochure). […] That is certainly different from 10 years ago.' – HCP21, nurse specialist

Professionals with many years of work experience saw these developments reflected in the behaviours of their patients, who generally had become more assertive over time. Examples included patients who initiated mobile recordings of their medical consultations, ordered wound care materials themselves or turned down supportive care offered by the treating healthcare institution because they had already arranged it elsewhere. However, professionals also expressed concerns about patients considered 'unwilling or unable to be in charge', as these patients are 'disadvantaged by the shift away from traditional, paternalistic medicine' and might subsequently 'fall behind', resulting in increased health inequalities between patients:

'Self-management has become increasingly proactive, because that is what the current healthcare system and society in general demand from patients. However, not all patients can keep up. […] So we run the risk that people are being left behind, especially the low-literate and the people who do not see any examples in their environment or just do not have the intelligence to manage it all.' – HCP01, medical specialist

As shown by abovementioned statement, healthcare professionals experienced self-management to be highly dependent on patients' skills and available resources. Multiple other patient characteristics were mentioned to be important as well. Cultural and religious backgrounds, for example, were thought to affect self-management through their influence on language skills, acceptance of disease and impending death, the status and authority ascribed to healthcare professionals, and prevailing convictions, such as a 'Calvinistic reluctance to take pills'. While professionals considered some associations clearly present at a population level, such as the use of proactive and persevering strategies by patients with young children, they frequently noted the pitfalls of generalisation in individual patient care. They illustrated this with examples of patients who had surprised or otherwise impressed them with their self-management:

'Currently, I am treating a patient whose oncologist gave him a free hand to take pain medications. A high-educated person. Yet, last week, he told me he is not able to do it, because he cannot estimate what to do.' – HCP08, nurse specialist

'We once treated a lady with ovarian cancer. [...] She had two little children. Probably, she could have survived, but she decided to forgo chemotherapy. A pretty woman with beautiful hair, who just absolutely did not want to lose that hair. While we assumed... well, I do not care about my hair so much... so I expected another choice.' – HCP20, nurse specialist

The nearing end of life was experienced to have a large impact on patients' self-management, especially when it came rather unexpectedly and patients were still actively involved in life. According to some professionals, a persistent will to survive or fear of death could cause patients to conduct 'desperate', 'extreme' or 'unrealistic' searches for potentially life-prolonging, yet risky and costly treatment options:

'With the cannabis oil, for example. Patients go looking for it themselves, but everyone can put anything on the internet and claim to be an expert. And if you are a layman and you have just been told that you are incurably ill, then you are amenable to everything. […] Those are the people who go to Germany for unproven invasive treatments.' – HCP21, nurse specialist

Conversely, healthcare professionals also experienced that for other patients, the news about their prognosis was so overwhelming that it 'confused' or even 'paralysed' them. Furthermore, professionals described how the prospect of impending death could lead patients to reconsider their values and priorities and rearrange their lives, resulting in changing ways of self-management:

Box 2
Healthcare professionals' challenges to dealing with self-management of patients with advanced cancer.

1. Institutional or educational barriers, e.g. insufficient opportunities (e.g. time), knowledge or skills:

'Just giving a patient his diagnosis, treatment plan and a bit of explanation about the side effects versus additionally discussing his priorities, preferences, values, meanings, [...]. The latter is a completely different conversation, which takes more time. However, in the current hospital payment structure, there is no reward for scheduling extra consultations, except for my own feelings of integrity.' – HCP01, medical specialist

'What complicates it (dealing with self-management) is that I am used to thinking traditionally. We used to do all the thinking for the patient […]. "Madam, now we are going to do this and then we are going to do that." We would not even consider giving that lady a t-shirt and letting her put it on herself. That is how I was trained.' – HCP04, nurse

2. Discrepancies between patients' self-management strategies and professional opinions or responsibilities:

'One of my patients has advanced colon cancer and she is doing all kinds of vague alternative and experimental treatments, also abroad. For us that is very difficult, because there is no transparency about what happens. Yet, if complications occur, this patient comes to our hospital, expecting us to resolve them. This becomes increasingly problematic, especially since it concerns a growing patient group.' – HCP05, nurse

'In the hospice, we just had a patient who did not want any nursing care and insisted on doing everything himself. That drove us crazy. We told him that we had to check on him at least three times a day. […] Eventually, he told us that this was very much against his will. […] It had a huge impact on our team, so we are going to evaluate this case.' – HCP09, general practitioner

3. Doubt or disapproval regarding the influence of informal caregivers on patients' self-management:

'I just asked a patient about her medication and then that lady said: "My husband knows all that". Or when I ask a patient about his stools and he looks at his partner. […] I have difficulty with that, because it means that someone has fully relinquished his self-management to relatives. Also, I see many relatives who completely take over self-management. By forcing a patient to eat, for instance.' – HCP08, nurse specialist

Box 3
Healthcare professionals' roles in self-management support for patients with advanced cancer.

1. **The instructive role**: Directing patient self-management based on professional expertise; the healthcare professional is leading.*'Self-management works well when patients have the instructions and the recipes and have already read these when coming to the hospital, so that they can follow our steps. Patients who can accept and follow advice… If a patient allows you to take him by the hand, I don't mean to be patronizing, he will deprive himself a little less.' – HCP08, nurse specialist*

2. **The collaborative role**: Integrating professional-directed and patient-directed strategies, using a clear and well-delineated division of tasks between professional and patient.*'Patient and professional both need something from each other. The patient needs my knowledge and the pros and cons of everything and I need to know what suits the patient, what type of person he or she is and how he or she lives and used to live.' – HCP15, medical specialist*

3. **The advisory role**: Following patient-directed strategies using a holistic approach; the patient is leading.*'You should listen rather than talk to your patients. The most important thing is to give them the opportunity to bring up whatever they want to discuss, because these are often things you would not have thought about.' – HCP12, general practitioner*

'I treated this neurologist, the most rational neurologist ever. He got a tumour and became interested in spirituality and started using alternative medicine. He himself found it strange as well, but told me he felt a very strong need to try it. So sometimes, you see people change when the end is near.' – HCP09, general practitioner

3.3. Attitudes and challenges regarding self-management of patients with advanced cancer

Some professionals were optimistic about self-management of their patients with advanced cancer, considering them to 'know more than they think they know', 'be less and less surrendered to the almighty medical world' and 'become more and more empowered'. Others, who focused more on patients' participation in medical care and treatment, were sceptical, indicating that they 'noticed little self-management' and that patients who do participate are 'the ones they remember at the end of the day'.

Irrespective of their preponderant attitudes, healthcare professionals indicated that self-management of patients with advanced cancer posed considerable challenges for professional care and treatment, arguing that their jobs had become 'bigger' and 'more varied'. Furthermore, patients' self-management prevented them from 'working on the autopilot', as they 'had to keep up to date', also about matters that used to be outside of their professional scope, such as lifestyle hypes. According to different healthcare professionals, dealing with self-management was especially challenging or even disturbing in case of incongruity between patients' strategies and their professional circumstances, capabilities, opinions or responsibilities (see Box 2). Difficulties also arose when care and support from informal caregivers were experienced inconsistent with the patient's best interest.

3.4. Healthcare professionals' views on their own roles in self-management support for patients with advanced cancer

In reaction to their experiences, attitudes and challenges regarding self-management of patients with advanced cancer, healthcare professionals expressed different views on their own roles in self-management support for these patients. We identified the following three roles: 1) instructive; 2) collaborative and 3) advisory (see Box 3). Whereas some healthcare professionals preferred or inclined to adhere to one of these three roles, others indicated to switch their roles, depending on the situation.

3.4.1. The instructive role

In the instructive role, healthcare professionals tried to direct and stay in charge of self-management of patients with advanced cancer. Directions mostly concerned strategies related to managing the disease and medical care, such as monitoring and controlling symptoms and maintaining activities of daily living. Healthcare professionals often expressed a large sense of responsibility for their patients to understand and comply with their instructions:

'I have created treatment diaries, in which patients should monitor their symptoms and compliance with therapy. Yet, if I do not explain this, nothing happens. You need to keep repeating and checking whether the patient can follow you.' – HCP08, nurse specialist

Instructions could pose limits to patient-directed self-management activities, but were considered necessary to achieve individual healthcare and treatment goals, which were also mainly focused on disease and medical care and included 'improving symptom control and quality of life', 'keeping a patient on treatment as long as possible' and 'increasing patients' awareness of their medication regimens and reasons to call for medical assistance'. Furthermore, 'optimal' self-management would contribute to more efficient and effective care, thus also benefiting the healthcare professional and the overall healthcare system. Hospital culture was mentioned to foster instructive approaches. Compared to the other professional disciplines, nurse specialists referred to these approaches most often, especially if they cared for patients receiving experimental clinical treatments:

'Patients have signed a treatment agreement, which involves expectations and obligations. Of course I want to think along about how it suits them best, but the fact remains that they are on a leash, because otherwise the treatment will be at risk.' – HCP18, nurse specialist

3.4.2. The collaborative role

In the collaborative role, healthcare professionals integrated their professional support strategies with patient-directed strategies. Collaboration with patients was realised by establishing a clear and well-delineated division of complementary tasks between professional and patient. Healthcare professionals wanted patients to reflect on their personal circumstances, needs, values and preferences and considered these in their care and treatment policies. Yet, they also expected patients to rely on their professional expertise and consider this in their daily life:

'Patients who research scientific studies down to the smallest detail […]. They function on a high level and find a lot of information, but still lack the medical knowledge to interpret it correctly. […] That is something we should try to avoid.' – HCP01, medical specialist

If they found patients' self-management behaviours incompatible with their professional expertise or protocols, they would intervene by finding an alternative everyone agreed on:

'*The art is to make sure that patients are satisfied when they leave the room, yet, without that referral letter or that pot of weed they insisted on, because (providing) that would be such a waste of time,*

or a waste of the drug.' – HCP21, nurse specialist

Healthcare professionals who adopted a collaborative role indicated that self-management support had succeeded if patients would have 'received care and treatment that incorporated their personal values and circumstances'. Better interprofessional collaboration, for instance by means of 'more appropriate referral to supportive care disciplines, such as psychology', was also explicitly mentioned as a goal that would benefit both patient self-management and professional self-management support. In their stories about the work experience they had gained, healthcare professionals often signified a shift from instructive towards more collaborative self-management support roles:

'Filling your backpack is something you do throughout your career. At a certain point, this baggage gives you an overall picture, which makes you understand that you do not always have to stick to protocols and decision trees. It is not either A or B; it may be a combination of both. Gradually, you learn to make those combinations faster and deal more flexibly with the patient and his personal wishes.' – HCP05, nurse

3.4.3. Advisory role

In the advisory role, healthcare professionals adjusted their professional support strategies to patient-directed strategies, organising and arranging care and treatment starting from the needs and preferences articulated by the patient. Patient self-management as well as professional self-management support were approached holistically and could include the more personal aspects of a patient's life:

'Currently, I am treating a patient with advanced hereditary breast cancer, who has entered the rollercoaster of radiotherapy, surgery, chemotherapy, everything. However, with me she prefers to talk about ordinary things, such as the wig. So for some patients, you are more like a confidant.' – HCP06, general practitioner

The personal, holistic approach of healthcare professionals who adopted an advisory role was also reflected by their statements about the goals of self-management and self-management support, which included that patients would 'make choices that suit their personalities' and 'keep living besides their illness'. As long as neither the patient's safety nor their own feelings of integrity were compromised, healthcare professionals with an advisory style left patients free in their self-management behaviours and their decisions about the frequency and intensity of professional support:

'One of my patients had a colossal tumour just below the knee. […] She did not want to be referred […] or talk about death. As soon as I steered the conversation in that direction, she cut it short in all kinds of creative ways. [...] I think that is something we (healthcare professionals) have to respect.' – HCP12, general practitioner

Some professionals suggested that gaining life experience had encouraged them to adopt advisory approaches:

'My own mother passed away last year. […] It taught me things I now apply in my work, like starting from the needs patients express. Because now I know it was most supportive when healthcare professionals just asked us how we were doing. I already knew that, but now I feel it even more.' – HCP26, nurse

3.4.4. Determining the appropriate self-management support role

Healthcare professionals often explained that they based their self-management support roles on specific characteristics of their patient populations. However, because of deviating views and preferences, they responded differently to similar populations:

'Among patients with head and neck cancer, there are quite some people who avoid regular care and have unhealthy lifestyles. […] We struggle with the responsibility for these patients and then often take on the paternal role.' – HCP02, medical specialist

Versus:

'Compared to general populations, homeless people tend to be even more autonomous in their self-management. For example, that woman who seized every opportunity to obtain drugs. [...] Of course, we tried to address the issue, but it would happen anyway. Moreover, it was her way of self-managing.' – HCP20, general practitioner and street doctor

Likewise, the fact that patients were incurably ill and at the end of life influenced professional support roles in various ways. Several participants explicitly mentioned that they approached patients with advanced diseases less instructive compared to patients with chronic diseases:

'In chronic care, you try to let people live as healthy as possible. In advanced cancer care, the goal is to promote quality of life in the last phase. [...] Self-management support really serves a different purpose then.' – HCP06, general practitioner

Another reason for being less instructive was a lack of professional consensus about the options for end-of-life care and treatment:

'Of course, I think patients should know the consequences of their actions, but the thing is that with these patients (with advanced cancer), we often have no idea (about these consequences). So who am I to say what someone should or should not do?' – HCP14, medical specialist

On the contrary, other professionals pointed out that the enormous impact of advanced cancer on patients' lives led them to adopt a more instructive support role:

'Many patients, including clever and organised people, are so overwhelmed by emotions that they are trapped in a state of collapse. […] They need a professional who tells them "This is how we are going to do it".' – HCP15, medical specialist

The large impact of the end of life increased healthcare professionals' sense of urgency to adopt the appropriate self-management support role, because they felt that, just like patients and their loved ones, they themselves 'would have no chance to do things over again' either, and because 'loved ones will always remember the end-of-life trajectory, especially if self-management and self-management support do not work out well'.

Eventually, the match between the various characteristics of professional and patient determined whether the healthcare professional perceived his self-management support as successful and satisfactory:

'I am lucky with my patients, because I like to explain things and give advice, while they like to get explanations and follow advice. But should I change my approach if a patient would not like it? That would be very hard.' – HCP18, nurse specialist involved in experimental clinical trials

Many healthcare professionals attempted to enhance this match by tailoring their support role to the individual patient they were working with. They did so by 'exploring the patient's background and context', 'observing a patient's body language', 'feeling and reading the patient', 'identifying the question behind a question', and 'building a trusted relationship with the patient'. Furthermore, self-reflection and becoming aware of one's own preferences,

expectations and convictions were declared essential for determining the appropriate self-management support role:

> *'Ideally, self-management will make patients feel resignation, catharsis. However, that is very much how I see it. […] By contrast, many of my patients want to have tried everything and remain in control until their last breath. As healthcare professionals, we need to become aware of our own beliefs and realise that these do not necessarily have to coincide with those of our patients or colleagues. […] Therefore, we must be careful with our own projections.' – HCP14, medical specialist*

4. Discussion and conclusion

4.1. Discussion

4.1.1. Experiences, attitudes and challenges regarding self-management of patients with advanced cancer

This interview study showed that healthcare professionals in various medical and nursing disciplines experienced self-management of patients with advanced cancer to be highly individual, diverse and potentially dynamic. Their attitudes towards self-management varied from mostly optimistic to sceptical, with more scepticism observed among professionals who concentrated on medical aspects. Professionals unanimously mentioned that self-management posed significant challenges to their care and treatment. Despite observing this population becoming increasingly proactive and enterprising in its self-management, they expressed concerns about patients who cannot or do not want to live up to the expectation of being actively engaged in their healthcare. Moreover, proactive, patient-directed strategies conveyed substantial difficulties for professionals as well. Our study confirms previous findings indicating that self-management of these patients is not always compatible with professional care and expertise [16,22,36–40], for example, when patients choose to withhold relevant information about their symptoms. Also, patient self-management goes largely beyond the professional care setting, while nevertheless affecting care and treatment within that setting. In this regard, professionals frequently discussed their experiences with patients who made rigorous lifestyle changes or started using complementary and alternative strategies that could alter the safety and effectiveness of regular medical therapies. In general, healthcare professionals seemed to have more difficulty with self-management when they could not reconcile patients' or their relatives' strategies with their own professional circumstances, capabilities or responsibilities, or their ideas about what sensible self-management would entail.

4.1.2. Roles in self-management support for patients with advanced cancer

In this study among healthcare professionals from various medical and nursing disciplines, we identified three different roles in self-management support for patients with advanced cancer: 1) instructive, directing self-management based on professional expertise; 2) collaborative, using a well-delineated division of complementary tasks between patient and professional; and 3) advisory, following patient-directed strategies using a holistic approach. Previous studies also used typologies to describe healthcare professionals' self-assigned and performed roles in patient-professional relationships [26,28,41–46]. However, these studies differ from our study in several ways: they examined these roles from other, either narrower or wider angles, such as decision-making [44], goal-setting [43] and patient-professional communication in general [41,42,45]; focused on chronic disease populations [26,28] or general patient populations [41,42,44,45]; included only a single type of healthcare professionals, such as nurses [26,28,46] or physicians [41,42,45]; or based typologies on theoretical rather than empirical findings [41,42]. Consistent with two studies that examined nurses' self-perceived roles in self-management support for patients with chronic diseases [26,28], we found that the scope of self-management support varied from predominantly biomedical (in the instructive role) to holistic (in the advisory role). However, while both nursing studies derived their typologies primarily from such differences in self-management support content, in our study, differences in self-management support style, i.e. the degree of initiative and control taken by healthcare professionals, emerged as the main and most univocal criterion for classification.

The healthcare professionals in our study indicated that their self-management support roles were shaped by patient characteristics. The influence of the end of life of patients seemed to be bi-directional. On the one hand, a lack of professional medical consensus and a shifted focus towards preference-sensitive care and treatment decisions could cause professionals to take on a more accommodating, advisory support role. On the other hand, the 'extreme', 'desperate' or 'paralysed' ways in which some patients were considered to self-manage at the end of life resulted in more controlled, instructive support roles. Differences in professional self-management support styles thus seemed to be a response to the divergence experienced in self-management strategies of patients with advanced cancer. However, professionals attributed preferred and adopted roles not merely to their patients, but also to other, work-related and personal factors, such as their work setting and the life experience they had gained. These findings endorse the hypothesis raised by Been-Dahmen et al., who questioned whether the absence of an expected association between nurses' self-management support views and their patients' characteristics could be explained by an attenuating or overruling effect of nurses' personal characteristics [26]. Our results also corroborate prior findings indicating that physicians assess self-management support from a broader, more holistic perspective if they have experienced adversity themselves [47]. Most importantly, adopted support roles were not static, but rather dynamic, resulting from interactions between professionals, patients and their environments.

4.1.3. Methodological considerations and future research

This study expands the scope of our knowledge and understanding of patient self-management and professional self-management support by adding novel insights from the context of advanced disease and the perspective of different healthcare disciplines involved. Its qualitative design and heterogeneous study population enabled a phenomenological examination of the variation in healthcare professionals' views. However, this method also has limitations, as it may fail to uncover unconscious, implicit ideas and actual behaviours during patient-professional encounters. Furthermore, a lack of saturation within categories of certain characteristics, such as professional setting, hampers firm conclusions about the nature and direction of their associations with self-management support roles. Further research needs to test the hypotheses generated in this study, which for instance suggest that instructive self-management support roles are more prevalent within hospitals compared to other care settings. Future studies could also investigate distributions of the different support roles in a larger sample, including professionals from supportive care disciplines, such as psychologists and chaplain workers. Also, these studies could examine other relevant background characteristics, such as the cultural and religious backgrounds of healthcare professionals. Additionally, future studies using longitudinal methods and audio-visual aids might be able to scrutinise the dynamics between patient self-management and professional self-management support in actual care practice and over time. Finally, it is important to study what healthcare professionals in different self-management support roles need in order to fulfil these roles in a satisfying, self-congruent and effective way.

4.2. Conclusion

Self-management is not only challenging for patients with advanced cancer, but also for the professionals involved in their care: they need to support a wide variety of patients with versatile and potentially dynamic self-management styles, activities, preferences and needs. Moreover, patient self-management is not always consistent with professional care and expertise. While some healthcare professionals predominantly applaud patients' strategies, others express more hesitant attitudes. Healthcare professionals hold different views on self-management support in advanced cancer, adopting instructive, collaborative and advisory roles. Whereas some of them prefer or incline towards one of these roles, others adjust or switch roles, depending on the interactions with patients and their environments.

4.3. Practice implications

Just as patients with advanced cancer have different approaches to self-management, healthcare professionals differ in their approaches to self-management support for these patients. Instructive, collaborative and advisory self-management support roles will therefore all be appropriate and useful under certain circumstances. Also, it might be unfeasible and even undesirable to expect all healthcare professionals, regardless of their work setting and discipline, to become proficient in all self-management support roles. Nevertheless, professionals who are able and willing to adopt multiple self-management support roles can meet the needs and preferences of a larger diversity of patients. Regardless of their preferred or adopted support roles, healthcare professionals could facilitate patient self-management by being aware of their own preferences, expectations and convictions, and communicating these clearly to their patients and colleagues. We therefore recommend that all healthcare professionals involved in care for patients with advanced cancer receive education and training that, besides practical self-management support skills, teach skills to increase self-knowledge and critical self-reflection. Additionally, evidence-based models, such as the 5 A model for nurses [48], and innovative didactic strategies, such as experience-oriented learning [49], could be further developed and used. This could help to stimulate a synergetic exchange between experienced and recently graduated healthcare professionals and to integrate healthcare professionals' practical and theoretical expertise in self-management support for patients with advanced cancer. Within education, one should encourage the debate about how patient self-management relates to professional care and treatment, and what this means for the organisation and responsibilities of healthcare.

CRediT authorship contribution statement

All authors (SD, RS, LK, HN, FW, CR, AH and JR) made a substantial contribution to the concept and design of the study. SD, RS and JR recruited participants for the interviews. SD, RS and JR collected the data by conducting the interviews. SD, RS and JR analysed and interpreted the data. LK, HN, FW, CR and AH actively contributed to the interpretation of the data. SD wrote the first draft of the manuscript. All the other authors critically revised the manuscript. All authors have sufficiently participated in the work to take public responsibility for appropriate portions of the content and approve the final version of the manuscript to be published.

Declaration of competing interest

The authors (SD, RS, LK, HN, FW, CR, AH and JR) declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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