A Qualitative Study Exploring Models of Supportive Care in Men and Their Partners/Caregivers Affected by Metastatic Prostate Cancer

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Purpose/Objectives: To explore the experiences of patients with metastatic prostate cancer and their partners/caregivers, as well as an interprofessional team, with a nurse-led multimodality supportive care intervention.

Research Approach: Qualitative study.

Setting: National Health Service (NHS), Tayside, Scotland.

Participants: 19 patients, 7 partners/caregivers, and 7 interprofessional members from four hospitals in NHS, Tayside, Scotland.

Methodologic Approach: 33 semistructured interviews were conducted to explore patients’ and partners/caregivers’ experiences of supportive care, and a framework approach was used to analyze the data.

Findings: Men and their partners/caregivers experienced a range of unmet physical, psychological, and informational supportive care needs. The participants in the intervention group reported overall high satisfaction with the use of holistic needs assessments and self-management plans, with a decrease in unmet needs compared to the standard of care over time. The prostate cancer specialist nurse was perceived as the hub of survivorship care. Members of the interprofessional team perceived benefit in the nurse-led multimodal supportive care intervention.

Interpretation: An emphasis needs to be placed on personalizing care, with supportive care interventions targeted to individual needs.

Implications for Nursing: Care can be improved by incorporating holistic needs assessment to target specialized interventions for optimized, individualized care plans. An intervention seminar encouraged self-management and self-efficiency, leading to greater satisfaction for participants.

More than 330,000 men live with prostate cancer in the United Kingdom, and more than 44,000 are diagnosed with prostate cancer each year (Prostate Cancer UK, 2016). In the United States, more than 3,085,209 live with prostate cancer, and about 161,360 will be diagnosed in 2017 (National Cancer Institute, 2017). Newer palliative therapies for metastatic prostate cancer have improved survival rates (Gilson, Manickavasagar, & Chowdhury, 2015), so a larger number of men are requiring ongoing supportive care.

Treatment for metastatic prostate cancer aims to reduce systematic testosterone levels, which can be achieved surgically or chemically by chemical castration (also known as androgen deprivation therapy [ADT] or androgen suppression therapy) (National Institute for Health and Care Excellence, 2014). Men undergoing ADT experience a range of symptoms that negatively affect quality of life and increase the need for supportive care interventions. Side effects...
identified as particularly challenging include (a) body feminization; (b) changes in sexual performance; (c) relationship changes; (d) cognitive and affective symptoms; and (e) fatigue, sleep disturbance, and depression (Carter, Miller, Murphy, Payne, & Bryant-Lukosius, 2014; Fitzpatrick et al., 2014; Grossmann & Zajac, 2011; Kornblith, Herr, Olman, Scher, & Holland, 1994; Lewis, Khan, & Payne, 2013; Wittmann et al., 2009).

Studies have identified that unmet supportive care needs are prevalent in contemporary health care (Paterson, Robertson, Smith, & Nabi, 2015), with a particular focus on individuals affected by metastatic prostate disease (Donovan, Walker, Wassersug, Thompson, & Robinson, 2015; McLeod, Walker, Wassersug, Matthew, & Robinson, 2014; Paterson, Kata, Nandwani, Das Chaudhury, & Nabi, 2017; Ream et al., 2008; Walker, Hampton, Wassersug, Thomas, & Robinson, 2013; Walker, Tran, Wassersug, Thomas, & Robinson, 2013). Supportive care is a person-centered approach to meeting the informational, spiritual, emotional, social, or physical needs of people with cancer during diagnosis, treatment, or follow-up phases. This care involves health promotion and prevention, survivorship, palliation, and bereavement (Polley et al., 2016). The consequences of metastatic prostate cancer and treatment side effects affect not only men but also their partners/caregivers. Partners/caregivers can experience unmet needs related to care burden, relationships or sexuality, and physiologic distress (Bobridge, Bond, Marshall, & Paterson, 2015; Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2010; Donovan et al., 2015; Kornblith et al., 1994; McLeod et al., 2014).

The current study aimed to gain an understanding of men and their partners/caregivers affected by metastatic prostate cancer and their experience of a multimodal supportive care intervention called ThriverCare compared to the experience of men and their partners/caregivers receiving standard care. The experience of supportive care was explored from the perspectives of patients and partners/caregivers and the interprofessional [INT] team. The primary endpoint was the experience of unmet supportive care needs at three months of the intervention compared to no intervention.

**Methods**

This study will report the qualitative component of a subset of participants from a feasibility randomized, controlled trial (RCT). The design of the RCT is shown in Figure 1. Ethical approval was obtained (16/ES/0024) following review of protocol by North East of Scotland Ethics Committee.

**Intervention: ThriverCare**

The intervention was comprised of four main components: a holistic needs assessment, individualized self-management care plans, a group-based seminar, and educational materials. The intervention and associated materials were developed in consultations with INT healthcare experts, including patient representatives.

**Holistic Needs Assessment and Individualized Care Plans**

The intervention group (patients and their partners/caregivers) completed the Holistic Needs Assessment (MacMillan, 2017) and patient-reported outcome
Patients in the control group completed the PRO questionnaire, the PCSN met with each patient and his partner/caregiver and used the information collected from the questionnaires to direct discussion to identify supportive care needs and tailor a self-management support intervention accordingly.

The PCSN was asked to document supportive care needs identified during the consultation and any subsequent evidence-based interventions initiated based on the questionnaire assessment. The Model of Consultation for Prostate Cancer Care (Paterson & Nabi, 2017) and evidence-based guidelines for the nurse-led care delivery of treatment and management of metastatic prostate cancer were used to inform the intervention (Paterson, Alashkham, Windsor, & Nabi, 2016).

**ThriverCare Seminar**

The half-day self-management seminar covered the following topics: introduction to ADT and potential side effects, self-management of side effects, management of emotions and mind changes, erectile dysfunction and relationships, nutrition and exercise, finance and benefits, relaxation and stress management, and guidance regarding community-based services and an open-question session with a PCSN. The seminar also provided a custom-made evidence-based self-management booklet titled *A Prostate Cancer Guide to Thrivership: Men, It Is Time to Thrive*.

**Standard of care:** Patients in the control group received the standard of care that was offered at clinical sites. This involved three monthly outpatient clinic reviews with a consultant urologist or medical staff member with prostate-specific antigen testing. Participants randomized to standard care did not complete PRO questionnaires, receive evidence-based self-management plans, or attend self-management seminars.

**Data collection:** Exploratory purposive semi-structured interviews were conducted using a topic guide informed by existing literature, the primary outcome, and the classification of supportive care needs at three months (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2011; Hui, 2014; Paterson et al., 2015; Rittenberg, Johnson, & Kuncio, 2010) (see Figure 2). This interview guide focused on participants’ experience of the provided care, the advantage and disadvantage of the two models, and the feasibility and implementation of the intervention in current care.

Purposive sampling of the interviews ensured maximum variation by patients’ age (range = 67–84 years), socioeconomic background (Scottish Index of Multiple Deprivation, ranging from 1 [most deprived] to 5 [least deprived]), time since diagnosis (7–56 months), and the prevalence of the number of existing comorbidities (range = 0–5). The study sample was designed to enable the researchers to explore some diversity in the men’s and partners/caregivers’ experiences of follow-up care. The common themes were continually reviewed. Field notes were written immediately following the interviews to record any

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**FIGURE 2. Interview Guide**

- Can you tell me about the care and treatment that you have received?
- Can you tell me what you think about the care you have received from healthcare professionals (at the hospital [doctors, nurses, allied health professionals], in the community [general practitioners, community nurses, practice nurses], and out of hours [National Health Service 24-hour phone service])?
- Can you tell me about the experience of coordinating hormone injections and taking tablets?
- What information have you been provided with about prostate cancer, treatment, and potential side effects?
- What information have you been provided with about the symptoms you may experience during your hormone therapy?
- Can you tell me about the experience of living with the side effects? Do you talk about the side effects with your care team? If not, why? What specific side effects do you experience? Are they distressing to you or your partner/caregiver?
- Do you read the written information you are given on hormone treatment and potential side effects? If no, why? Did you find the information helpful?
- In general, how do you feel about the support that you have received from your healthcare providers?
- Can you tell me about positive experiences of follow-up care?
- How do you find traveling to your clinical appointments in regard to time and cost?
- Do you use any support groups? If not, why?
- Are there any improvements that might be made that could have enhanced the care you received?
- What could have been done better for you?
- What has been your experience of the care you have received?
- What is your greatest concern about prostate cancer? How does it affect your general life?
- What is your greatest concern about prostate cancer? How does it affect your general life?
- Additional questions for intervention group
  - What did you think about the seminar? What was good and bad about it?
  - What did you find most helpful from the seminar?
  - How could we improve it, or was there anything you would have liked to do differently?
  - What did you think about the time of day and length of the seminar and travel to and from the seminar?
  - What did you think about the thivership booklet?
conversations before and after the formal interview. Data saturation was reached when no new information related to the experience of care or themes was identified during the interview process.

**Rigor:** To ensure rigor of the study, the following concepts were used: credibility, transferability, dependability, and confirmability, as identified by Lincoln and Guba (1985). The researcher conducting the interviews ensured credibility by audio recording impressions, thoughts, and notes and reflecting on them immediately after each interview. In addition, the interview data were checked by peers to verify the identified themes. Transferability was conducted by providing a detailed description of the study setting and sample. Dependability was addressed from the audit trail from the research group through research notes for the decision-making process as the study progressed, as well as during the analytic process. Confirmability was ensured through clarification with open-ended and repetitive questioning during interviews, the reflective process after interviews, and peer discussion for data interpretation and verification.

**Description of interview:** Most of the interviews were conducted in the participants’ homes or in a cancer care center. Interviews were audio recorded with the patient’s written consent. The interviews began with an open-ended, nondirective question to encourage participants to speak about their experiences of follow-up care. Open-ended probe questions were also used to elicit greater detail of experiences shared by participants.

**Analysis of qualitative and quantitative data:** The semistructured interviews lasted 40–90 minutes. Recordings were transcribed verbatim and cross-checked for accuracy, and identifying information was removed. One of the authors coded all the interviews, and coding was subsequently verified by a second and a third author, when needed, to ensure a close match. Framework analysis was used to examine commonalities and differences within and between the transcripts. Broad themes were identified, and an electronic matrix display (in Microsoft Excel®), which included original links to the data, was used to keep a transparent account of how themes were derived. Triangulation strategies included comparison of the study results with those of previous studies conducted in the patient population (Carter et al., 2011; O’Brien et al., 2011; Ritchie, Lewis, Nicholls, & Ormston, 2013) and with the data collected from the prospective questionnaire survey.

**Results**

In total, 19 patients, 7 partners/caregivers, and 7 INT members consented to participate in semistructured interviews across four hospitals in the National
ONCOLOGY NURSING FORUM • VOL. 44, NO. 6, NOVEMBER 2017

Health Service, Tayside, Scotland. See Tables 1 and 2 for clinical and demographic characteristics.

Qualitative themes clearly emerged across the standard of care and intervention groups. In the standard care group, certain themes related to a range of unmet supportive care needs (physical, psychological/emotional, intimacy/sexual, patient/clinician communication) emerged. Participants in the intervention group reported overall high satisfaction with the intervention and acceptance of PROs in routine clinical practice.

The Standard Group

Physical needs: The main physical needs were related to managing the long-term side effects of ADT, and men spoke mainly about grappling with tiredness, loss of enthusiasm, weight gain, and hot flushes and how these affected their daily lives. Other men associated lack of energy and weakness to the aging process rather than therapy, and had resigned themselves to accepting these issues as unavoidable. Men articulated a lack of self-management support in managing these side effects.

I would have liked some advice on how to cope with this tiredness. (Partner 6/1)

I am tired most of the time. . . . I used to do a lot of do-it-yourself stuff, help neighbors—that sort of stuff. Can’t do that anymore. I don’t have the energy. My whole attitude towards work has changed. I can’t be bothered. (Patient 160/0)

Psychological/emotional needs: Around the time of diagnosis, concerns of fear of death and dying were common across all participants and partners/caregivers. The participants were worried about their cancer no longer being a curable disease and having to come to terms with their treatment continuing for the rest of their lives. In addition, men and their partners/caregivers expressed uncertainty about the treatment and progression of cancer. Men and their partners/caregivers were unsure of how often the extent of metastases would be assessed and how their care team would otherwise monitor their condition. Also, men perceived a lack of compassion for their emotional needs from their care team:

Is it going to spread more? And how would they know, other than asking [the specialist nurse] if he could have a scan to see if it was spreading? (Partner 7/1)

I was handed a leaflet. I was told that I would have hormone treatment and, if that didn’t work, then they would try something else. Fine. And that was the end of the story. (Patient 3)

Daily practical/financial needs: The ADT and travel to hospital appointments did not cause a burden on the daily practical needs of most men, but men vocalized frustration related to a lack of motivation and the effect it had on their lives. Other couples spoke about the financial implications and consequences of the man living with a palliative cancer diagnosis:

I can’t be bothered a lot of times. My enthusiasm and motivation for doing things [have] virtually disappeared. I am not interested anymore. I don’t know what the word I am looking for really is . . . loss of enthusiasm, really. I can’t be bothered. (Patient 160/0)

I mean, I gave up my work. I was due to retire, but I gave up my work earlier. . . . I would have probably carried on working as I was not due state pension until now, but I do get an occupational pension as well. I took the decision to be the career. But I just felt that I was not giving my best to my job, and so I felt it was time to stop. (Partner 15/1)

Intimacy/sexual needs: Most participants accepted the inevitable consequence of ADT on intimacy and changes in relationships, which did not adversely affect the quality of life of most men or their partners. Most couples were comforted that they still had each other, seemed to appreciate their continued companionship, and accepted the adjustment in their intimacy. However, change in sexual function had a major negative impact on some couples’ quality of life, which was a struggle to adjust to. Men also spoke about changes in their masculinity related to alterations in their appearance from hormone treatment:

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<th>TABLE 2. Interprofessional (INT) Team Characteristics (N = 7)</th>
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You weigh it all up, I would rather have [patient 150/1]. I would rather have companionship and [patient 150/1] than a sex life, you know, life changes and priorities, you know. Rather companionship, I just put up with it. (Partner 15/1)

It’s just a male thing, isn’t it? . . . You don’t want these things. . . . Got boobs, do you? Sometimes I am a bit embarrassed about that—dare I say nipples are starting to protrude a bit? (Patient 70/1)

Patient/clinician communication: Patients perceived that the time during consultations was limited and primarily focused on blood results rather than overall holistic care and self-management advice. Generally, patients felt they lacked clinical information on their diagnosis and treatment and expressed frustrations about not fully understanding the information or implications of treatment.

They honestly don’t really discuss anything more. [The clinician] checked the blood and then [said] see you in three months or so. (Patient 4)

[The clinician] said it was prostate cancer, and [my husband] had hot spots. But they never explained to us what the hot spots were and where they were. (Partner 6/1)

Intervention Group

Men and partners/caregivers perceived that they had derived benefit from this model of care. Certain themes clearly emerged as important to participants, including being listened to by someone who could facilitate emotional expression, being provided individually tailored information, and receiving practical help and evidence-based advice for managing the consequences of cancer and its treatment.

Emotional support: Patients and partners/caregivers felt that they were given time to share their emotional concerns with the PCSN during consultations and felt that their symptoms were given appropriate consideration through the use of the PROs. Patients felt that their diagnosis and treatment were explained to them by the PCSN in language they could understand and perceived that they were supported in the clinical setting and that they could reach out to the PCSN for additional emotional support.

[The specialist nurse] answered my questions when I asked about what hot spots [were], and she explains it to you in detail and you understand what she is saying. Since we have come into contact with the specialist nurse, we have been able to ask her things, because she sits and listens to you and asks you questions. (Partner 6/1)

Informational support: Across all participants in the intervention group, no unmet informational needs were perceived. However, one patient expressed difficulty contacting the PCSN by telephone for informational support but was able to contact the nurse through email. Many patients and partners/caregivers viewed the role of the PCSN as the hub of survivorship care, and observed that the PCSNs were part of an INT team that provided additional support for them. One patient expressed unmet informational needs that were addressed after a later consultation with a PCSN.

[The PCSN] has definitely been able to answer my questions. She’s been very good. She knows her job, and she’s got so many experts [members of the interprofessional team] around her, you know, to help her. (Patient 100/1)

I did not know it was a hormone treatment, because . . . only when I met the specialist nurse, I then knew it was hormone treatment and how it worked. I assumed it was maybe a form of chemotherapy before. It was not explained to me. (Patient 30/1)

Evidence-based self-management plans: All participants in the intervention group agreed to complete PRO questionnaires prior to meeting with the PCSN in the outpatient setting, which allowed for systematic assessment of supportive care needs. Most participants’ main concerns were related to lack of energy and fatigue, which facilitated discussion of referral to tailored exercise programs, with other men reporting benefits from self-management plans. Others reported PRO concerns in relation to hot flushes, which allowed tailored self-management plans.

[The prostate cancer specialist nurse] put me through for the Keep Fit, Movement for Life. (Patient 100/1)

They went through [the PRO questionnaire] very carefully and seemed quite happy that the worst thing to me was the sweats. The specialist nurse did offer me alternative options help and a tablet to help me with the sweats, but I did not want to go down that road. I thought I could cope with the sweats. (Patient 100/1)

Evidence-based self-management seminar: All but one participant randomized to the intervention arm attended the seminar (participant was in the hospital and unable to attend). Patients and partners/caregivers perceived benefit in the intervention in the form of information and support. Participants felt they were given information in a clear and understandable manner, and reported that it was
educational to discuss the topics during the breaks with other participants. Participants also perceived benefit from the evidence-based self-management booklet and, generally, felt well advised on how to look after themselves at home after participation in the seminar.

Well, I read it and read it again—the booklet that we got at the seminar—and it’s quite handy. . . . I could have done with that booklet when I first got prostate cancer. They told us what treatment I was getting, and that’s that. But I didn’t really know much about the prostate cancer or how to look after myself, whereas that booklet told you a lot of stuff. I got a lot of information out of that. (Patient 70/1)

**Interprofessional Members**

Members of the INT team acknowledged that there were gaps in the current care model concerning informational needs, and they perceived benefit in the holistic approach to patient care with the nurse-led intervention model of supportive care and the addition of the seminar. Members of the INT team perceived the advantages to the intervention model of supportive care to be greater access to specialist nurses, the ability to target unmet supportive care needs through the routine use of PROs in clinical practice, and the scope to release consultant time for surgery capacity. In addition, follow-up care for this patient group with prostate cancer focuses on quality of life, and the seminar provided encouragement for self-management and greater self-efficiency.

Information about keeping active, diet, options for managing hot flushes, that keeping active is a way of managing fatigue, issues about how to manage impotence, erectile dysfunctions—there is a huge amount of information that, in an ideal world, if we had time, and the patient had time to absorb it all, you would give at the time of starting hormone treatment, but the problem is that it tends to be done in the middle of a fairly hectic clinic, and I don’t think that the information given about how to manage the side effects and the various physio-social effects of treatment we give is essential. (INT06)

Addressing the problems on toxicity they are having with the standard hormone treatment is perhaps not addressed in a systematic way. That would be my concern. I think that, generally, the nurse-led model intervention, I suspect, patients are having their toxicity and holistic needs addressed better than the cohort who are missing out. (INT06)

**Discussion**

This qualitative study aimed to understand patients’ and their partners/caregivers’ experience of two models of supportive care delivery for metastatic prostate cancer. To the authors’ knowledge, this is the first qualitative study to explore the experience of men with metastatic prostate cancer and their partners/caregivers, as well as the standard of care group and INT team, in a multimodal supportive care intervention. Few publications have included partners or caregivers, despite the acknowledgement of their needs in relation to care burden, relationship/sexual needs, and physiologic distress (Bobridge et al., 2015; Carter et al., 2010; Donovan et al., 2015; Hampton, Walker, Beck, & Robinson, 2013; Kornblith et al., 1994) and the influence of partners/caregivers on patients’ quality of life (Gustavsson-Lilius, Julkunen, & Hietanen, 2007; Walker, Hampton, et al., 2013; Walker, Tran, et al., 2013). Patients and their partners/caregivers can experience a range of unmet physical and psychological supportive needs (Paterson et al., 2016) irrespective of the clinical characteristics and length of treatment. This can include fears of cancer spreading, uncertainty of the future because cancer is not curable, needs related to intimacy and sexual desire, and a lack of personal holistic care as a support mechanism.

PROs are described as standardized and validated questionnaires completed by patients to evaluate their own perceptions of needs in relation to quality of life and symptom burden (Dawson, Doll, Fitzpatrick, Jenkinson, & Carr, 2010). PROs reveal patients’ and partners/caregivers’ highest concern, enabling healthcare professionals to personalize and develop self-management plans. Without PROs, symptoms and consequences of ADT may go under-recognized and undertreated within oncology practice, which was apparent in the current study’s standard care group. Effective assessment through PROs and care planning provided by the PCSN facilitated the identification of individual concerns and needs that prompted early interventions, improved communication, and personalized supportive care in this and in other studies (Greenhalgh, 2009; Robertson, Windsor, & Smith, 2013). Most patients in this study experienced concerns about the uncertainty of the future, death and dying, and cancer spreading, which are common experiences of patients living with cancer as a chronic illness (Mishel et al., 2009). Integrating the evidence-based seminar with PROs in routine clinical practice allowed for a tailored, personalized model of care and targeted self-management plans. The results suggest that implementing PRO measures in routine clinical practice across the INT can improve the supportive care experience.
In addition, the intervention seminar, which provided education to patients and their partners/caregivers on self-management of their individual needs, was beneficial. The self-management seminar promoted discussion of the diverse needs of patients and partners/caregivers. Self-management can be defined as the ability of an individual to manage symptoms, the effects of treatment, physical and psychosocial consequences, and lifestyle changes. Efficient self-management involves the ability to oversee one’s condition and to effect cognitive, behavioral, and emotional actions necessary to maintain a satisfactory quality of life. Within cancer literature, the term self-management refers to an iterative process whereby individual responses and behaviors are used to cope with the physical and psychological consequences of cancer rather than the prevention or elimination of symptoms (McCorkle et al., 2011). Effective self-management of cancer and its treatment can improve patients’ quality of life (Hammer et al., 2015). Targeting individuals’ needs across the broad spectrum of metastatic prostate cancer can be difficult in a routine clinical setting. In this study, the current authors observed that participants in the intervention group perceived empowerment in their self-management through participating in the seminar, reading the evidence-based self-management information booklet, and sharing experiences with others.

**Limitations**

The sample size was small and mainly consisted of White British participants, with limited follow-up. Some caution should be taken in the interpretation of these findings. The study should be repeated with a larger and more diverse sample, so that men from minority groups are equally represented. Also, information is lacking on the actual self-management behaviors performed by participants and how this affected their experience of supportive care, as well as if there are any differences in the experience of the care needs for men and their partners/caregivers based on the length of ADT.

**Implications for Nursing**

The results of this study can be used to inform nursing practice for men and their partners/caregivers affected by metastatic prostate cancer receiving ADT. In particular, this study has shown how the care of men and their partners/caregivers can be improved by a multimodal supportive care intervention. Incorporating holistic needs assessment in clinical practice allowed for a person-centered evaluation and targeted, individualized self-management interventions for optimized supportive care. One of the most important nursing implications is that the novel ThriverCare intervention decreased participants’ unmet supportive care needs over time. This study also highlighted the holistic care PCSNs can provide with the support of INT members. These results should inform management and care planning of men with metastatic disease on hormonal treatment.

Future studies of participants with other cancers should carefully consider targeting individuals with significant issues or unmet needs, and strive to deliver an individualized, flexible model of care. One size of care delivery does not fit all. Care must be responsive and adaptable to meet the individual needs of people affected by cancer.

**Knowledge Translation**

- The novel ThriverCare intervention for men and their partners/caregivers affected by metastatic prostate cancer decreased unmet supportive care needs over time.
- Future studies in other tumor groups should carefully consider targeting individuals with significant issues or unmet needs and strive to deliver an individualized, flexible model of care.
- Care must be responsive and adaptable to meet the individual needs of people affected by cancer to thrive.

**Conclusion**

Men and their partners/caregivers affected by metastatic prostate cancer seemed to benefit from the multimodal supportive care interventions in the short term, experiencing less unmet needs compared to the standard of care group. Future studies are encouraged to tailor interventions to individuals, as opposed to broad-targeting interventions, which are likely to be unsuccessful in optimizing self-management.

**References**


