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Exploring the Potential of Electronic Patient-Reported Outcome Measures to Inform and Assess Care in Sarcoma Centers

A Longitudinal Multicenter Pilot Study

KEY WORDS

Advanced nursing practice
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 Patient-reported outcome measures
 Sarcoma
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Background: Electronic patient-reported outcome measures (ePROMs) are useful tools to assess care needs of patients diagnosed with cancer and to monitor their symptoms along the illness trajectory. Studies regarding the application of ePROMs by advanced practice nurses (APNs) specialized in sarcoma care and the use of such electronic measures for care planning and assessing quality of care are lacking. **Objective:** To explore the potential of ePROMs in clinical practice for assessing the patient’s quality of life, physical functionality, needs, and fear of progression, as well as distress and the quality of care in sarcoma centers. **Methods:** A multicenter longitudinal pilot study design was chosen. Three sarcoma centers with and without APN service located in Switzerland were included. The instruments EQ-5D-5L, Pearman Mayo Survey of Needs, the National Comprehensive Cancer Network Distress Thermometer, PA-F12, and Toronto Extremity Salvage Score were used as ePROMs. Data were analyzed descriptively. **Results:** Overall, 55 patients participated in the pilot study; 33 (60%) received an intervention by an APN, and 22 (40%) did not. Patients in sarcoma centers with APN service reported overall higher scores in quality of life and functional outcome. The number of needs and distress level were lower in sarcoma centers with APN service. No differences were found with respect to patients’ fear of progression. **Conclusions:** Most of the ePROMs proved to be reasonable in clinical

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practice. PA-F12 has shown low clinical relevance. **Implications for Practice:** Using ePROMs appears to be reasonable to obtain clinically relevant patient information and to evaluate the quality of care in sarcoma centers.

Despite more than 100 subtypes, sarcoma is a rare disease with an incidence of approximately 400 cases per year in Switzerland.¹ Diagnosis, therapy, and care of patients with sarcoma are often challenging for healthcare teams because of their rare status.² The provision of good quality care requires a specialized, interprofessional, and multidisciplinary healthcare team that can address the complex care needs of the patients and their relatives.³ Overall, patients with sarcoma often experience heavy physical and psychological burdens caused by the indicated therapy, such as surgery, chemotherapy, and/or radiotherapy. These burdens also impact their families emotionally and financially.⁴ Healthcare professionals providing targeted information throughout the care pathway can support patients and their families to feel better informed about the care trajectory and to cope with the diagnosis and its multidimensional impact.⁵ However, there are only a few healthcare professionals in Europe with specialized knowledge in caring for patients with sarcoma who can provide the targeted care that is needed.⁶ In a bid to address the specific care demands related to the diagnosis, dedicated sarcoma centers were established.^{7,8} There are indications that such centers account for higher survival rates, better patient experience, and higher quality of care during the care trajectory, and especially at the end-of-life stage.^{9,10} Sarcoma centers were integrated into the Swiss healthcare system in 2013, and some centers have employed advanced practice nurses (APNs)¹¹ similar to other cancer care centers, for example, prostate cancer,¹² lung cancer,¹³ breast cancer,¹⁴ and hematological cancer.¹⁵ Advanced practice nurses are seen as an effective solution to address the complex care needs of patients with cancer and their relatives. The APN's multiple interventions, which are aimed at assessing standardized patients' and relatives' needs along the care trajectory and supporting each patient's self-management, result in timely care coordination within the interprofessional team and better patient outcomes in coping with the therapeutic adverse effects.^{10,16}

Electronic patient-reported outcome measures (ePROMs) are evolving to monitor symptoms and needs of patients diagnosed with cancer and to evaluate care quality.¹⁷⁻¹⁹ Patient-reported outcomes are understood as any report on the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.²⁰ Traditionally, patient-reported outcome measures are used for the quality assurance of medical treatment,²¹ but ePROMs can also be used as part of clinical practice and performance measurement.^{17,22,23} In this context, measures can directly inform the care planning, for example, by APNs, allowing them to take into account the patient's responses with respect to their symptoms and needs.^{19,24}

For example, one scoping and one narrative review summarized patient-reported outcome measures used with patients with sarcoma and concluded that quality-of-life outcomes and functional outcomes were used most often.^{18,25} On the other hand, measures assessing unmet needs and psychological outcomes were assessed less often because of differences in project aims.¹⁸ However, a common understanding that patient-reported outcome measures are necessary to monitor the quality of care in sarcoma centers is lacking.^{18,25} In

Switzerland, ePROMs are still innovative in cancer care, used to monitor cancer symptoms and to evaluate APN cancer services. Therefore, there are no accepted benchmarks in this context.^{26,27}

In summary, ePROMs present an innovative strategy to assess standardized cancer care needs and to monitor symptoms along the cancer care trajectory.²² Only one study could be found researching the implementation and use of ePROMs by APNs in cancer care,¹⁵ and another publication could be found describing the contribution and role of a clinical nurse specialist in a tertiary sarcoma referral service.²⁸ No study was found that addressed the use of ePROMs by APNs in the care of patients with sarcoma and how the electronic measures could inform the planning of care. Addressing the research gap, the objective of this pilot study was to support 3 sarcoma centers (2 with APN service, 1 without APN service) during the implementation of ePROMs as a preparatory step when planning for an experimental study.

■ Research Aim

The aim was to explore the potential of ePROMs as a tool to describe the quality of care in sarcoma centers and assess the patient's quality of life, physical functionality, the amount and burden of needs, and fear of progression, as well as distress in sarcoma center care.

■ Methods

Design and Study Sites

A multicenter longitudinal pilot study design was chosen.²⁹ This design is deemed most suitable to measure ePROMs at defined time points along the cancer care trajectory. Because of the status of sarcoma as a rare disease, a multicenter approach was chosen to ensure a sufficiently large sample size. Three university hospitals with certified sarcoma centers located in the German-speaking part of Switzerland were included. Two of the centers offer a specialized APN service; 1 center does not.

All 3 hospital sites are certified according to the requirements of the European Cancer Centre Certification Programme³⁰ and might have a comparable infrastructure for treatment and care provision for patients with sarcoma. However, information was provided by each hospital site to compare context criteria, such as operation technique and surgeons' experience, the number of operations per year, whether psychosocial care was provided, and the characteristics of the APN service. The main difference between the sarcoma centers was thus the implementation of an APN service; 2 sarcoma centers had implemented 1 APN each. In addition to the APN master's degree, one of the APNs held a postgraduate diploma in "interdisciplinary psycho-oncology counseling," whereas the other had started the diploma course. Patients in the 2 sarcoma centers with APN service received direct clinical support during the diagnostic and therapeutic

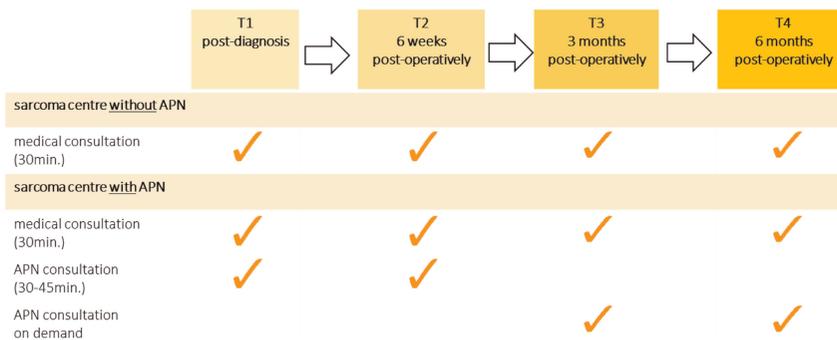


Figure 1 ■ Points in time of measurement and related care provision of the intervention and the comparison group. Abbreviations: APN, advanced practice nurse; T, point in time.

phases and on demand in the follow-up phase. Figure 1 summarizes the care provided in this study. The setup facilitated an analysis of whether ePROMs reflect the impact of an APN service.

Conceptual Framework

The conceptual framework used within this study and the foundation of the APN services for patients with sarcoma and their relatives is the person-centered practice framework.^{31,32} This framework is internationally recognized and follows the processes of empowering healthcare professionals to deepen and strengthen their relationship with the patient by being aware of the patient's beliefs and values, being sympathetically present, and engaging authentically. Providing holistic care by assessing patient needs along the illness trajectory and involving them in the shared decision-making process ensure person-centered nursing and might result in person-centered outcomes, such as good care experience, involvement in care, feeling of well-being, and a healthful culture. In the context of the APN services, person-centeredness is provided by interventions such as standardized consultation during diagnosis, treatment and follow-up until 6 weeks postoperative, clinical and holistic needs assessment, distress screening, psychoeducation, counseling, planning, and coordinating care in an interprofessional and interdisciplinary team. Interventions supporting the healthcare team are mentoring and coaching of healthcare professionals and assessing the needs of other healthcare providers in the interprofessional and multidisciplinary context.

Sampling and Recruitment

Patients were included when diagnosed with sarcoma of the upper or lower extremity that required surgical therapy during the study or shortly before. A list of all relevant diagnoses was defined and used for recruitment. In the sarcoma centers with APN service, patients were recruited by the APN; in the sarcoma center without APN service, a study coordinator recruited the patients. Patients were informed orally and in writing about this project and their rights and provided their consent to participate.

Participants had to speak and understand German or French. Furthermore, patients at a center with APN service had to have at least 1 consultation with the APN during their care trajectory. Excluded were patients who were younger than 18 years at the time of diagnosis, who had a cognitive impairment, who had received their treatment outside of the participating sarcoma centers, and/or whose follow-up care was planned abroad.

Outcome Measures

A literature review was performed to identify the most relevant outcome measures. Although no study was found that focused on APN services for patients with sarcoma, there are publications that support outcomes such as quality of life, functional outcomes, and aspects of mental health. Hence, the following patient-reported outcome measures were chosen.

- Quality of life—measured by the instrument EQ-5D-5L CH,³³ a reliable and valid questionnaire adapted for Switzerland; includes 5 items with general questions about, for example, mobility, pain, discomfort, fear
- Unmet needs—assessed by the Pearlman Mayo Survey of Needs (PMSN),³⁴ a valid and piloted questionnaire developed for patients with cancer by the Moncrief Cancer Institute; includes 50 items (needs) assessing, for example, daily living, emotional and spiritual needs, and the needs level of burden
- Distress—assessed by the National Comprehensive Cancer Network (NCCN) Distress Thermometer,³⁵ without screening of needs, which is an evaluated screening instrument to detect psychosocial distress in patients with cancer using a scale (thermometer) ranging from 0 (no distress) to 10 (extreme distress) to determine the magnitude of psychosocial distress in the last week
- Fear of progression—measured by the instrument PA-F12,³⁶ a reliable short-form questionnaire to assess fear of progression, consisting of 12 items about personal expectations regarding the course of the disease and possible future concerns
- Physical functionality—the Toronto Extremity Salvage Score (TESS),³⁷ an evaluated and validated questionnaire with 35 items assessing the patient's daily activities and physical functionality (eg, dressing, grooming, social participation)

The authors of these 5 instruments granted permission to use their questionnaires. To characterize the sample, data were also collected on education, personal circumstances, and information about therapies.

Data Collection

Data were collected between October 2020 and September 2021 (12 months) at 4 points in time: postdiagnosis (T1), 6 weeks post-surgery (T2), 3 months postsurgery (T3), and 6 months postsurgery (T4). Each hospital site used its own data collection software. Sarcoma centers with APN service used Lime Survey (version 3.28.17, LimeSurvey GmbH, Hamburg, Germany) or Heartbeat (version 7.27.0, HRTBT Medical Solutions GmbH, Berlin, Germany), and the center without APN service used REDCap (version 12.5.10, REDCap Consortium). On the day of hospital admission, participants were asked to provide an email address. The APN or study coordinator then provided a link to the ePROMs at the defined times. Patients without the opportunity to communicate via email received a

printed version of the PROM. At the end of the data collection phase, all results were anonymized and compiled into one final data set.

Data Analysis

The final data set was analyzed by means of descriptive statistics, including mean, minimum, maximum, median, and SD. The software packages used were Excel (version: 2019/1808; Microsoft Corp, Redmond, Washington), SPSS (version 28.0.1.0; IBM Corp, Armonk, New York) and R (version 4.2.1; R Foundation for Statistical Computing, Vienna, Austria).

EQ-5D-5L CH

A sum score was calculated based on an index value set provided by EuroQual.³² The sum score ranges from 0 to 1 on the scale. Then, all sum scores were summarized and calculated in descriptive means per point of time (mean, minimum, maximum).

PEARLMAN MAYO SURVEY OF NEEDS

Needs were identified when participants rated items at least with 1 on the Likert scale (0 = no burden to 5 = extreme burden). The numbers of needs were summarized by means of sum. The needs level of burden was then summarized by calculating mean, minimum, and maximum using the rating between 1 and 5.

DISTRESS THERMOMETER

The level of distress, ranging between 0 (no distress) and 10 (extreme distress), was calculated for each point of time by mean, minimum, and maximum.

PA-F12

The analysis was done by assigning a point value from 1 to a maximum of 5 for each item according to the scale. The higher the value,

the greater the burden. In addition, all points were added to a total value, which ranges from 12 to a maximum of 60 points. A high score corresponds to a strong expression of progression anxiety. In our study, the total score for all statistical evaluations was divided by 12 to obtain an averaged total score with a range of 1 to 5 points.

TORONTO EXTREMITY SALVAGE SCORE

Scores were calculated according to Trost et al.³⁷ Each item serves as a measure of the difficulty to complete the task. The total score for a unit means the best possible performance value (ie, 5). The scale was designed to allow participants to answer in a nonapplicable category even if patients do not perform it in their daily routine. Consequently, the total score of the questionnaire was calculated in a standardized way between 0 and 100: ((sum of total score - # items)/(possible score interval)) × 100%. Sum of item scores = sum of "impairment" response; # items = answered items excluding nonanswered items; possible score interval = (5 × # items) - (1 × # items).

Ethical Considerations

This study design was assessed by the ethics committees of all study sites, that is, Basel, Bern, and Zurich (Req-2019-00363/April 14, 2019). The study does not fall under the Swiss Human Research Act; therefore, it was performed in line with the principles defined in the Declaration of Helsinki.³⁸

Results

The 3 sarcoma centers recruited a total of 55 patients. Table 1 provides an overview of the sample characteristics. Of the participants, 33 (60%) were married or partnered; 22 (40%) were single, divorced, or widowed. Of the participants, 44 (80%) lived in

Table 1 • Sample Characteristics

	Total		SC1		SC2		SC3	
	n	%	n	%	n	%	n	%
Tumor location								
Upper extremity	13	24	3	21	6	29	4	20
Lower extremity	42	76	11	79	15	71	16	80
Type of sarcoma								
Soft tissue sarcoma	34	62	8	57	16	76	10	50
Bone sarcoma	20	36	6	43	5	24	9	45
No response/unknown	1	2	0	0	0	0	1	5
Therapy								
Surgery	47	86	12	86	21	100	14	70
Radiotherapy	25	46	9	64	10	48	6	30
Chemotherapy	6	11	1	7	4	19	1	5
No response/unknown	1	2	0	0	1	5	0	0
Length of hospital stay, mean/min/max, d	8/2/24		8/5/15		10/2/24		7/4/12	
Hospital readmissions within up to 18 d after discharge [n]	2		0		1		1	
Age, median/min/max, y	56/24/90		54/32/75		60/31/90		53/24/76	
Gender, n (%)								
Male	23/42		7/50		9/43		7/35	
Female	32/58		7/50		12/57		13/65	
Other	0/0		0/0		0/0		0/0	

Abbreviation: SC, sarcoma center.

a household of 2 or more persons, and 11 (20%) lived on their own. A university degree (bachelor, master, PhD) had 18 (33%), whereas other participants had completed compulsory school (6 [11%]) and further professional education (30 [55%]). One person did not provide information on his/her education.

Of the participants, 33 (60%) received an intervention by an APN, and 22 (40%) did not. The 55 patients provided a total of 119 responses, with decreasing response rate over time, that is, not all participants completed the different questionnaires at all points in time when they were invited to do so. This also holds true for the questionnaires sent before surgery. A total of 14 patients were recruited by sarcoma center 1 (SC1); they provided a total of 31 responses. The 21 patients of SC2 provided 51 responses, whereas the 20 patients of SC3 added 37 responses. Table 2 summarizes all responses for all instruments used. To illustrate the differences of centers with/without APN service, Figure 2 represents the results for the EQ-5D-5L CH, the PMSN (dimension burden), the NCCN Distress Thermometer, the PA-F12, and TESS. As can be seen, the scores of all 5 instruments indicate a similar starting point for all patients followed by an improvement for the group with APN service. Patients who were supported by an APN reported a constant number of unmet needs. The patients without an APN service indicated more unmet needs, which particularly increased between T2 and T3 (Table 2).

Differences in the number of needs were analyzed for all scales of the PMSN, that is, physical, emotional, spiritual, and social needs. Patients most often reported physical needs (8 needs

without APN service; 4 needs with APN service, median values) followed by emotional needs (7 vs 3 needs) and social needs (4 vs 2 needs). Spiritual needs were barely reported (median 0 needs for both groups). Figure 3 illustrates additional differences in the overall number of needs of patients between the sarcoma centers with APN service and without.

Discussion

This study reports on the use of ePROMs to monitor quality of care in sarcoma centers and to inform care planning. Quality of life, unmet needs, distress, fear of progression, and physical functionality were regarded as the most relevant measures in this context. Corresponding validated instruments were implemented in 3 sarcoma centers and ePROMs started at diagnosis and continued until follow-up care 6 months postsurgery. Generally, the implementation of the ePROMs was straightforward and worked reliably. Only a very small number of patients did not hold an email address; that is, the use of a digital format for recording patient responses was appropriate in our population.

Despite using validated instruments, the results obtained by the questionnaire regarding fear of progression (PA-F12) did not differ. In contrast to the other instruments, the outcome did not change from T2 to T4 or between centers with or without APN service. In view of studies on cancer survivors who reported high levels of fear of progression during the course of the disease,³⁴ a

Table 2 • Summary of the Results at Different Observation Points

	T1	T2	T3	T4
Responses obtained, n				
SC1 (with APN)	14	7	7	3
SC2 (without APN)	15	16 ^a	12	8
SC3 (with APN)	19	9	7	2
Patient-reported outcomes, mean, minimum, maximum				
EQ-5D-5L CH (max 1.00)				
With APN	0.82, 0.07, 1.00	0.83, 0.43, 1.00	0.88, 0.48, 1.00	0.87, 0.76, 1.00
Without APN	0.81, 0.29, 1.00	0.69, 0.36, 1.00	0.72, 0.00, 1.00	0.66, -0.02, 1.00
PMSN, dimension needs (max 50)				
With APN	12.96, 0.00, 50.00	12.95, 2.00, 27.00	12.52, 1.00, 30.00	13.33, 3.00, 34.00
Without APN	19.00, 0.00, 36.00	18.40, 3.00, 31.00	25.20, 8.00, 34.00	22.00, 10.00, 32.00
PMSN, dimension burden (max 5)				
With APN	1.71, 0.00, 3.39	1.60, 1.00, 3.39	1.47, 1.00, 2.63	1.69, 1.00, 2.88
Without APN	1.81, 0.00, 3.08	2.16, 1.00, 3.58	2.24, 1.13, 3.93	2.44, 1.50, 3.88
NCCN Distress (max 10)				
With APN	4.70, 0.00, 10.00	3.30, 0.00, 8.00	3.00, 0.00, 9.00	3.40, 1.00, 8.00
Without APN	5.10, 0.00, 10.00	5.70, 1.00, 9.00	5.70, 1.00, 8.00	6.70, 5.00, 9.00
PA-F12 (max 5)				
With APN	2.00, 0.00, 4.00	2.00, 0.00, 3.00	2.00, 1.00, 2.00	2.00, 1.00, 3.00
Without APN	3.00, 1.00, 4.00	2.00, 1.00, 3.00	2.00, 1.00, 3.00	2.00, 1.00, 4.00
TESS (max 1.00)				
With APN	0.83, 0.15, 1.00	0.72, 0.34, 1.00	0.85, 0.51, 1.00	0.88, 0.68, 0.98
Without APN	0.81, 0.23, 1.00	0.55, 0.19, 0.98	0.67, 0.27, 0.98	0.63, 0.24, 0.95

Abbreviations: APN, advanced practice nurse; PMSN, Pearlman Mayo Survey of Needs; SC, sarcoma center; T1, responses postdiagnosis; T2, responses 6 weeks postsurgery; T3, responses 3 months postsurgery; T4, responses 6 months postsurgery; TESS, Toronto Extremity Salvage Score; with APN, with APN service; without APN, without APN service.

Note: Thirty-three patients experienced an APN intervention, whereas 22 did not.

^aOne participant provided answers only from T2.

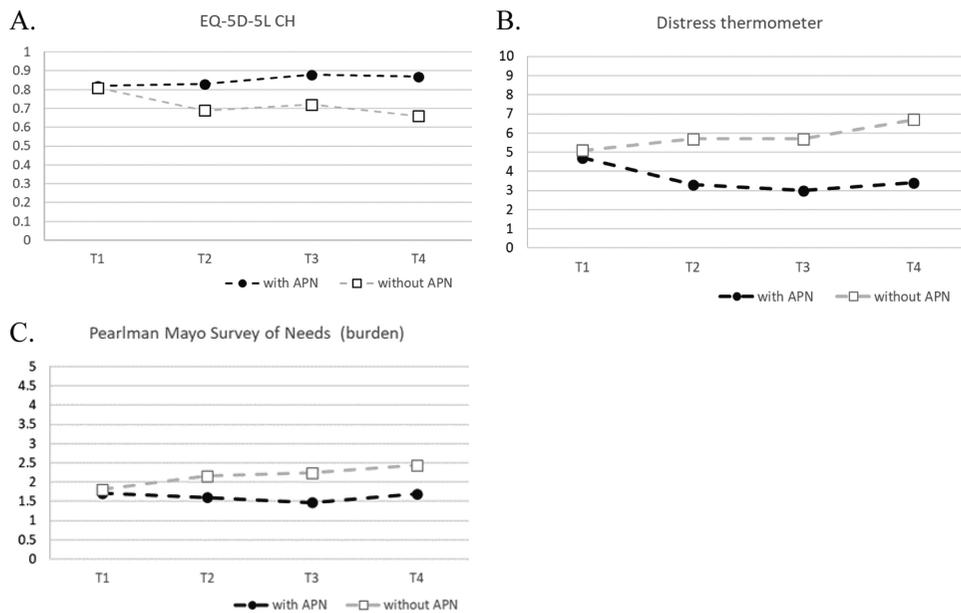


Figure 2 ■ Responses of the different instruments at the different observation times. The values represent the mean. A, EQ-5D-5L. B, NCCN Distress Thermometer. C, Pearlman Mayo Survey of Needs (dimension burden). Abbreviations: APN, advanced practice nurse; NCCN, National Comprehensive Cancer Network; T1, responses postdiagnosis; T2, responses 6 weeks postsurgery; T3, responses 3 months postsurgery; T4, responses 6 months postsurgery; with APN, sarcoma centers 1 and 3 with APN service; without APN, sarcoma center 2 without APN service.

difference in means between centers with and without APN service was expected, particularly due to the psychological interventions provided by the APN. Possibly, the sensitivity of the PA-F12 is too low for our population, or the intervention provided by the APN did not result in a detectable change, or our population was less concerned about progression of their disease at the times of measurement. Hence, this instrument or patient-reported outcome seems less useful for the purpose

studied here. It might be considered for use in future research for a longer measurement period to evaluate patient-centered interventions by APN.

Assessing the patients' quality of life using the EQ-5 L-5D CH seemed valuable in the context of sarcoma centers. The results of this questionnaire might give a comprehensive view of quality of care. They showed that sarcoma centers with APN services had higher scores for quality of life reported by the patients

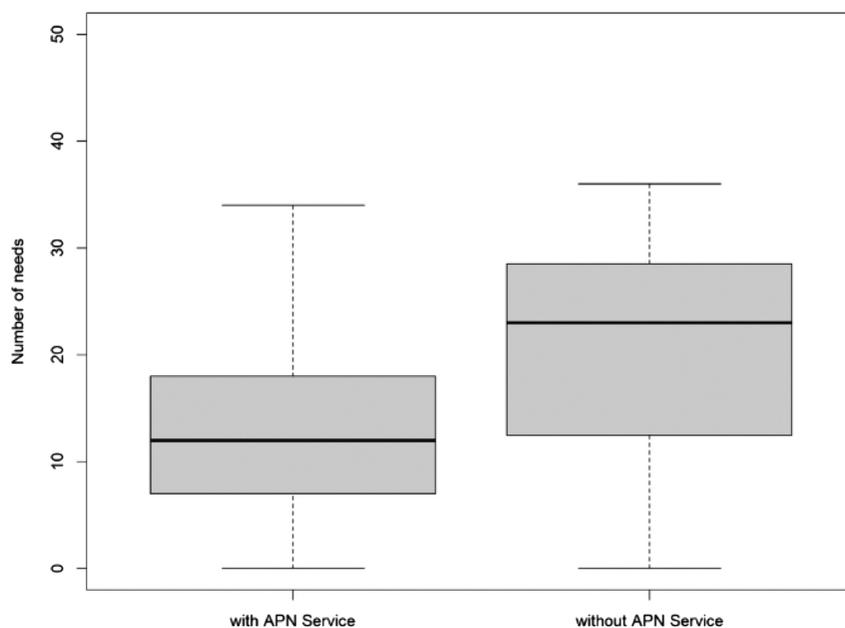


Figure 3 ■ Sum of all needs reported through the Pearlman Mayo Survey of Needs, that is, physical, emotional, social, and spiritual needs. The number of needs is lower in sarcoma centers with an APN service. Abbreviation: APN, advanced practice nurse.

compared with the center without an APN; this finding is in line with existing evidence summarizing outcomes for patients diagnosed with cancer following a nurse-led service by APNs.³⁹ However, it must be assessed if the outcome is suitable to both monitor patients diagnosed with cancer and their symptoms and evaluate APN services at the same time. Quality of life is a multidimensional concept that can be used, that is, to describe quality of care and a patient's health status.⁴⁰ However, further research is needed before a conclusion can be reached on the relevance and suitability of this outcome for care coordination by APN.

This study confirmed that unmet needs of patients diagnosed with sarcoma often increase over time, especially 3 and 6 months postsurgery. Similar findings were reported in a meta-analysis about cancer care coordination by Gorin et al.¹⁰ Identifying and coordinating unmet needs in an interprofessional and interdisciplinary team is one important intervention in APN cancer services and can positively impact patients and their families.¹⁰ The lower number of needs in the centers with APN service compared with the center without such service could indicate this. This could be interpreted as an indication of the effectiveness of an APN service. Without such a dedicated service, it can be more challenging to address unmet needs in outpatient and inpatient care in a timely fashion and result in a lower mortality rate.⁴¹ By using the PMSN, in contrast to the Distress Thermometer, the number of needs and the level of burden of reported needs can be gathered and thus facilitate targeted care planning. However, the number of items the PMSN entails, 50 in total, could be a barrier to keeping patients motivated to complete the entire questionnaire.

The Distress Thermometer is commonly applied to screen the level of distress experienced by the patient within the last week because it is acknowledged as a reliable and robust tool for individual patient groups with different cancer diagnoses. Although specific reference values for patients with sarcoma are lacking,⁴² for example, explored differences in psycho-oncological care for patients with prostate cancer where nurses provided a psychoeducational intervention and found similar results as in our study, the Distress Thermometer was by far the shortest questionnaire, which is considered beneficial in clinical practice.

Again, the APN service appeared to be able to effectively support the patients as the scores obtained were lower compared with the center without APN service. Providing psycho-oncological interventions, such as psychoeducation, decision and peer support, and supportive counseling, seems to positively influence patients' well-being.

Overall, patients reported high physical functionality sum scores in this study compared with other studies using TESS in patients with lower-extremity soft tissue sarcoma⁴³; in this study, highest scores were reported in sarcoma centers with APN service. The scores generally could reflect the high quality of care provided by the sarcoma centers. However, a power analysis is needed to collect data from enough replies per point of time to reliably make such conclusions. Considering the patient-centered practice framework,³² APN services providing psychoeducation and counseling might positively influence both psychological and functional outcomes. Whether an APN intervention can indeed result in patients experiencing and thus reporting a higher functionality remains to be investigated. Furthermore, specific interventions initiated by the APN that are based on the monitoring of needs, such as the PMSN, may have had an influence on higher

functional outcomes. For clinical use, TESS seemed to be a helpful instrument to receive information on the patient's physical condition and to plan specific interventions.

In summary, 4 of the 5 chosen ePROMs seem relevant to consider when aiming for an experimental study design. However, the outcome quality of life seems to be more valuable when evaluating the quality of care provided by an APN and their service instead of monitoring the disease and informing the planning of care. On the other hand, patient-reported outcomes such as unmet needs, the needs level of burden, and distress would further support a person-centered practice during the diagnosis, treatment, and follow-up phases of the illness trajectory. However, future research about the quality of care in sarcoma centers with APN service might comprise a bigger sample size recruited during a longer period (eg, 24 months) to identify differences in means/medians, for example, with an observational multicenter study design. Taking into account that neoadjuvant therapies may have an impact on patients' needs and burdens and also bear the risk of having undesirable effects, the addition of another time point by the end of a neoadjuvant therapy, and thus before surgery, should be considered.

Strengths and Limitations

This pilot study has strengths and limitations. Overall, the study addresses patients with a rare disease. Recruiting a sufficiently large sample in such a population is challenging for future projects. This holds particularly true if expected effect sizes are unknown and cannot be estimated from previous publications related to the target population, as this was the case here. This study, therefore, used a convenience sample. Although the multicenter approach was reasonable, the number of specialized sarcoma centers is small in Switzerland. Context factors such as differences in the structures of sarcoma centers might influence the patient experience. Only one center without APN service was included. For the 2 centers with APN service, it must be noted that there was only one APN per center. While the underlying APN care concepts of the 2 centers followed a similar approach, the interventions of the 2 APNs were not identical because of differences in participated psycho-oncological course work. In addition to the impossibility of performing an initial sample size calculation, this was the reason for omitting a more detailed statistical analysis of the results. The descriptive analysis of the responses, particularly related to the impact of an APN service, did indicate a trend, but not results for generalizability.

Although the implementation of ePROMs and the use of validated instruments are regarded as a strength, the user-friendliness of the approach was somewhat limited by the length of the questionnaires and the large number of items. This might have resulted in some dropouts in the comparison group. For clinical practice, the number of questionnaires used should be reconsidered.

Despite several limitations, this pilot study added knowledge on using ePROMs in a specific population of patients diagnosed with cancer. This contribution is important as the field of sarcoma care by APNs is underresearched.

Implication for Practice

The use of ePROMs appears to be reasonable to obtain clinically relevant information, but also allows an evaluation of quality of care, in particular, the impact of an APN service. The feedback

through ePROMs offers the possibility of automatically feeding the reported outcomes into clinical documentation of the corresponding patient such that the information about clinical and supportive care needs is easily available and enables an APN to address those needs. A logical model of the APN concept is necessary to identify the outcomes that are most relevant to assess the quality of care in sarcoma centers. Furthermore, implementing ePROMs in clinical practice sustainably might be best addressed by a stepwise approach and, for example, the use of implementation science.¹⁷

Implications for Research

Research with patients of rare diseases is challenging with respect to, for example, recruiting a sufficiently large sample. The results of this pilot study show that a multicenter longitudinal design is a suitable approach. Although the findings are preliminary, the effect sizes established here allow the sample size for a follow-up study to be calculated effectively.

Conclusion

The results of this multicenter longitudinal pilot study highlight the usefulness of ePROMs to evaluate and monitor patient outcomes in sarcoma centers with and without an APN cancer service. The questionnaire EQ-5D-5 L, the PMSN (both dimensions of number of needs and burden), and the NCCN Distress Thermometer seemed particularly suited to this context. The findings of this study suggest that an APN service has a positive impact on sarcoma patients. Future research should investigate the latter effect in more detail and should also address potential impacts of psychosocial or psycho-oncological interventions, respectively, on functional outcomes such as physical functionality.

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