

Patients' experiences with cancer care in Switzerland: Results of a multicentre cross-sectional survey

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Abstract

Objectives: The objectives were to describe patients' experiences of cancer care in Switzerland and explore the variation of these experiences by type of cancer.

Methods: The Swiss Cancer Patient Experiences (SCAPE) study was a cross-sectional, multicentre survey conducted in 2018. Adult patients ($n = 7145$) with breast, prostate, lung, colorectal, skin or haematological cancer from four large hospitals in French-speaking Switzerland were invited to complete a survey. Logistic regressions were used to assess whether experiences varied according to cancer type, adjusting for confounders.

Results: Of the 3121 persons who returned the survey (44% response rate), 2755 reporting an eligible cancer were included in the analyses. Participants' average score for overall care was 8.5 out of a maximum score of 10. Higher rates of positive experiences were found for nurse consultations (94%), diagnostic tests (85%) and inpatient care (82%). Lower positive responses were reported for support for people with cancer (70%), treatment decisions (66%), diagnosis (65%) and home care (55%). We observed non-systematic differences in experiences of care by cancer type.

Conclusions: This large study identified that cancer patient experiences can be improved in relation to communication, information and supportive care aspects. Improvement efforts should target these areas of care to enhance responsiveness of cancer care.

KEYWORDS

cancer, patient experiences, patient satisfaction, patient survey, quality of care, Switzerland

1 | INTRODUCTION

The importance of integrating patients' perspectives into clinical practice and research as well as into the evaluation of the quality of care has been recognised internationally (Institute of Medicine Committee

on Quality of Health Care in America, 2001; Kelley & Hurst, 2006). More specifically, patients' perspectives are key to evaluate responsiveness of care. This core dimension of quality of care is defined as care that responds to people's physical, emotional, social and cultural needs, where interactions with health professionals are

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compassionate and empowering, and where people's values and preferences are taken into account ("What Is Patient-Centered Care?", 2017; The Health Foundation, 2016). Collecting patients' experiences of care through surveys using self-reported questionnaires is a widely used method to evaluate responsiveness of care on a large scale (Cleary, 2016; McKenna, 2011; Snyder et al., 2013). These surveys ask patients to rate their experience and satisfaction with health services, including experiences during hospital care, general practice care and home-based care. While earlier studies focused on patient satisfaction, more recent studies questioned its frequent ceiling effects and limited responsiveness. Consequently, studies shifted their focus on the underlying components of satisfaction, i.e. expectations and experiences, by collecting reports of what actually happened to patients during a hospital stay or medical consultation (Sixma et al., 1998). These reports, called patient-reported experience measures (PREMs), are also more actionable to drive interventions to improve responsiveness of care (Coulter et al., 2020).

In cancer care, evaluating responsiveness of care is especially relevant, as cancer carries an emotional, social and financial burden on patients and their carers in addition to the health burden and impact on quality of life. The use of cancer-specific PREMs are encouraged to account for the complex treatment pathways and to improve the interpretation of findings and prioritisation of quality improvement initiatives (Abel et al., 2014). Several countries have thus established wide-scaled measurement of cancer-specific PREMs to systematically examine cancer patient experiences. Such initiatives include the CAHPS Cancer Care survey in the United States (Agency for Healthcare Research and Quality, 2017), the NHS Cancer Patient Experience Survey in the UK (Abel et al., 2014), and the European Cancer Consumer Quality Index survey in six European countries (Wind et al., 2016). To date, similar standardised initiatives do not exist in Switzerland. Despite the efforts of the Swiss National Association for quality development in hospitals and clinics (ANQ) to collect PREMs using a 6-item generic questionnaire (Groupe qualité interdisciplinaire Satisfaction des patients [QA PatZu], 2017), no large-scale, comprehensive or systematic collection of cancer-specific PREMs has been established in Switzerland to date. This lack of standardised experience surveys might partly be related to the late implementation of a national quality commission in Switzerland, founded in 2021 only. There is thus a gap in measuring PREMs with a standardised instrument in routine cancer care in Switzerland, as well as a gap in Swiss research to inform and promote the use of PREMs in cancer care. To our knowledge, only a few studies focusing on cancer experiences in Switzerland have been published in the last 10 years, one of which was a single site qualitative study in paediatric oncology (Wangmo et al., 2016) and another one including breast cancer patients only (Brédart et al., 2013).

The assessment of experience variations according to cancer type is relevant to determine whether systematic differences of care exist. Such analyses can inform the development of more targeted interventions within organ-specific cancer centres for instance. However, the current understanding of the variation of PREMs by organ (i.e. cancer diagnosis) is still limited, as large national surveys with sufficient patients diagnosed with different cancers enabling such analyses are relatively recent, with

few studies investigating the impact of type of cancer on patient experiences (Saunders et al., 2015). Previous studies have reported mixed results, with better experiences reported in general for breast cancer and skin cancer and worse experiences for prostate and colorectal cancers (Bone et al., 2014; Clucas, 2016; El Turabi et al., 2013; Heerdegen et al., 2017; Pham, Abel, et al., 2019; C. Saunders et al., 2016; Sherlaw-Johnson et al., 2008). The observed differences could be explained by clinical features of different cancers, such as the diagnostic processes, the treatment burden and the prognosis, as suggested by Saunders and colleagues (Saunders et al., 2015).

The primary objective of the Swiss Cancer Patient Experiences (SCAPE) study was thus to describe the experience of care of patients with cancer treated in large hospitals in the French-speaking region of Switzerland. The secondary objective was to explore the variation of experiences of care by type of cancer, adjusting for confounders.

2 | METHODS

2.1 | Study design and population

The SCA study was an observational cross-sectional multicentre survey of patients diagnosed with cancer in four large hospitals in the French-speaking region of Switzerland. The patient inclusion criteria were pre-defined as all adult Swiss residents (≥ 18 years) with a confirmed diagnosis of one of the six most frequent cancers in Switzerland (i.e. breast, prostate, lung, colorectal, skin or haematological cancer [leukaemia, lymphoma and myeloma]) and who had had at least one hospitalisation or outpatient visit in an oncology unit at the recruiting hospital between 1 January 2018 and 30 June 2018. The diagnostic inclusion criteria was limited to six cancer types with high prevalence in Switzerland, based on the estimations of minimum sample size for the planned analyses by cancer types and the feasibility of the study. Patient selection procedure was performed by the local hospital teams, through manual review of patient lists in two hospitals and through data inquiries in electronic databases (including diagnostic codes) in the other two hospitals.

2.2 | Data collection

All data were collected using a paper and pencil or electronic self-administered questionnaire. The paper questionnaire (with the option of completing the survey online) was sent out by each hospital to patients' home end of October 2018. A reminder was sent to non-respondents in January 2019. Individuals who returned the questionnaire by the end of March 2019 and reported at least one of the eligible cancers were included in the analyses.

2.3 | Measures

The questionnaire was structured into three sections (Section 1: experiences of care; Section 2: cancer and health characteristics; Section 3:

socio-demographic and economic characteristics) and space was provided at the end for free-text comments. The analyses of the free-text comments have been reported elsewhere (Arditi et al., 2020).

Section 1 on experiences of care included 46 evaluative questions on experiences of care (i.e. questions asking patient to evaluate an aspect of care), based on the 2016 version of the NHS Cancer Patients Experience Survey (CPES), originally developed in the UK (NHS England, 2021). With their approval, questions were translated into French and culturally adapted following international guidelines (Cull et al., 2002; Wild et al., 2005). The section included 14 subsections related to patient experiences throughout the care pathway, spanning from cancer diagnosis to follow-up care in the community (e.g. diagnostic tests; communication about the cancer diagnosis; decision-making about the cancer treatment and hospital care as inpatient). Seven of these subsections had filter questions, asking patients to answer only if they had had the targeted healthcare service (e.g. diagnostics tests, a hospitalisation or an ambulatory visit) within the last 12 months. Most questions had a 4- or 5-point Likert-type scale response options (e.g. *yes, completely; yes, to some extent; no; not applicable; and don't know/can't remember*); eight questions had binary response options (yes/no). The section ended with an overall satisfaction item (0 to 10 rating scale).

Section 2 on cancer and health characteristics included 15 questions on cancer diagnosis and treatments, other health conditions (list of 12 chronic conditions), overall health status (excellent, very good, good, poor, bad), quality of life (FACT-G7) (Yanez et al., 2013), two questions on depression symptoms (Whooley et al., 1997), and psycho-social characteristics (e.g. health literacy). Self-reports of cancer diagnosis and treatments were used as they have been extensively used in epidemiological and clinical studies and shown to be valid and sensitive (Kool et al., 2017; Navarro et al., 2006).

Section 3 on socio-demographic and economic characteristics included 12 questions, such as age, sex, principal language (French, other), living status (alone/couple, with/without children, other), education, professional occupation, and financial hardship.

2.4 | Data analyses

For the descriptive analyses, the percentage of patients reporting a positive experience (dichotomous variable) was computed for the 46 evaluative questions, according to the methodology developed by the original CPES team (NHS England, 2021). After excluding the neutral (i.e. 'Don't know/can't remember') and not applicable answers from the calculation, the proportion of positive experience answers (i.e. 'yes, definitely') was calculated from the remaining sample for the 46 evaluative questions. The percentages of positive experiences were colour-coded by 10% segments to visually assess levels of positive experiences in Table 2. The proportion of positive experiences (i.e. the proportion of 'yes, definitely' for patients who answered more than 50% of the questions in the subsection) was also averaged across patients for each of the 14 subsections of the questionnaire.

The percentage of positive experience was compared across types of cancer, using Pearson's chi-square test (or Fisher's test if the number

of events in a category was under five). Univariate logistic regressions were used to calculate unadjusted odds ratios (OR) and 95% confidence intervals (CI) of reporting a positive experience by type of cancer for each evaluative question ($n = 46$) and overall satisfaction. This was followed by multiple logistic regressions to evaluate the associations between type of cancer and positive experiences of care, adjusting for five major confounders for patient satisfaction reported in previous studies (Abel et al., 2014; Hargraves et al., 2001) (age, sex, health status, education and financial hardship) and for the recruiting hospital. For each logistic regression, a likelihood ratio test was performed to estimate the p -value associated with the main independent variable of interest, that is, type of cancer. Patients reporting more than one eligible cancer ($n = 128$) were excluded from the analyses by type of cancer as they could not be assigned to one cancer group.

The intraclass correlation coefficients obtained from mixed-models with a random effect for each hospital were calculated for all evaluative questions. As they were all below 0.01, the effect of clustering by hospital was considered to be negligible and thus multilevel modelling not necessary. All p -values were corrected for multiple testing using the False Discovery Rate method (Benjamini & Hochberg, 1995). Complete case analysis was performed; all statistical analyses were conducted with Stata 16.1.

2.5 | Patient involvement

A Patient Partner, co-author of this paper, was involved in the research process. She took part in the study steering committee and participated in pre-testing the questionnaire, writing the patient materials sent with the questionnaire, answering patient inquiries by email during the recruitment phase, analysing the open comments, preparing and writing the lay summary of results sent to participating patients, communicating the results on social media, and disseminating the study to the scientific community.

3 | RESULTS

3.1 | Participants' characteristics

Among the 7145 individuals invited to participate in the survey, 3121 completed the survey (225 completed it online [7.2%]), resulting in a 43.7% participation rate. Participants who reported a non-eligible cancer diagnosis were excluded from the analyses ($n = 366$), leading to 2755 participants (344, 372, 498 and 1541 in each hospital) included in the descriptive analyses. The number of respondents included in the calculated percentage of positive experiences for each evaluative question of the first section of the questionnaire (Q1 to Q46) varied between 626 for Q33 (22.7% of sample) and 2729 for Q7 (99.1% of sample), with a median of 1500 respondents (54.4% of sample) (see Table 2).

Participants' mean age was 63.9 (standard deviation [SD] 12.8) and 61% of respondents were women. Eighty-one percent of respondents reported a first cancer, the most common cancers being breast

TABLE 1 Respondents' sociodemographic and clinical characteristics

	N (%) or mean (SD)
Sex	
Women	1670 (61.0%)
Men	1068 (39.0%)
Age	
mean (SD)	63.9 (12.8)
18–34	61 (2.3%)
35–44	145 (5.4%)
45–54	390 (14.5%)
55–64	680 (25.3%)
65–74	861 (32.0%)
75–84	470 (17.5%)
85+	80 (3.0%)
Education	
Primary	429 (16.0%)
Secondary	1347 (50.2%)
Tertiary	909 (33.8%)
Professional status	
Active	737 (27.1%)
Disability or sick leave	293 (10.8%)
Retired	1431 (52.7%)
Other	254 (9.4%)
Principal language	
French	2634 (86.4%)
Other	373 (13.6%)
Had trouble paying household bills in past 12 months	
Yes	569 (21.0%)
No	2138 (79.0%)
Type of diagnosis	
First cancer	2168 (80.5%)
Recurrence	275 (10.2%)
2nd or 3rd cancer	249 (9.3%)
Time since first treatment	
<1 year	741 (27.7%)
1–5 years	1281 (47.8%)
>5 years	656 (24.5%)
Treatment(s) received	
Surgery	1669 (61.1%)
Chemotherapy	1573 (57.9%)
Radiotherapy	1426 (52.5%)
Hormonotherapy	759 (27.9%)
Immunotherapy	354 (13.0%)
Other therapy (target, transplant)	242 (8.9%)
None	40 (1.5%)
Co-morbidities	
≥1 chronic disease other than cancer	1582 (59.2%)
None	1090 (40.8%)

TABLE 1 (Continued)

	N (%) or mean (SD)
Overall health status (0–100 excellent)	
mean (SD)	52.6 (20.6)
Excellent/very good	674 (25.0%)
Good	1563 (57.9%)
Poor/bad	462 (17.2%)
Depressive symptoms in past month	
Yes	999 (36.8%)
No	1715 (63.2%)
Quality of life (FACT-G7 0–28 excellent)	19
mean (SD)	19.2 (4.4)

cancer (40.1%) followed by haematologic cancer (15.9%), lung cancer (15.0%) and colorectal cancer (10.5%). About half (47.8%) were first treated between 1 and 5 years before completing the survey. Details of participants' sociodemographic and clinical characteristics are presented in Table 1.

3.2 | Overall satisfaction and experiences of care: Global results

The overall satisfaction (Q47) was rated at a mean 8.5 (SD 1.4). The percentage of patients reporting positive experiences ranged from 36.5% (Q45) to 96.1% (Q15) (see Table 2). Over 80% of respondents reported positive experiences with timely access to specialist care (Q1), timely access to and information about diagnostic tests (Q2, Q3 and Q4), explanations about different treatments (Q9), communication with specialist nurses (Q14 and Q15), most aspects of hospital care as inpatient (Q18, Q19, Q20, Q22, Q25, Q26 and Q28), availability of documents during ambulatory care (Q30), information before the radiotherapy (Q32), GP receiving enough information (Q42) and administration of care (Q46). However, less than 60% of respondents reported positive experiences in relation to being told they could bring someone at diagnosis (Q5), receiving written information at diagnosis (Q8), being offered practical advice and support for side effects (Q11) and information about long-term side effects (Q12), information for family to help at home (Q36), about social support during and after treatment (Q37 and Q38) and financial support (Q41), and receiving a care plan (Q45). The results are graphically summarised using radars presenting the average positive experience score by subsection of the questionnaire (see overall line in Figure 1).

3.3 | Overall satisfaction and experiences of care: By type of cancer

Overall satisfaction (Q47) varied according to cancer, with patients reporting skin cancer rating their overall care the highest and patients reporting breast cancer the lowest (see Table 2). When adjusting for

patients' characteristics and the hospital, individuals with prostate cancer were the least likely to be satisfied overall (see Table 3).

Experiences of care varied significantly by type of cancer for 11 evaluative questions, without being systematically more positive (or negative) in all areas of care for one type of cancer (see Table 3 and Figure 1; the details of the 95% CI of unadjusted and adjusted ORs are provided in Table S1). Results showed that patients reporting colorectal cancer were the least likely to report positive experiences for waiting time before diagnostic test (Q3), information on long-term side effects (Q12), hospital care as inpatient (Q23, Q26 and Q27), and radiotherapy (Q35 and Q36). Individuals with breast and lung cancers were the most likely to report positive experiences of care for at least a quarter of the evaluative questions: especially in the subsections 'support for people with cancer' and 'inpatient care' for breast cancer and in the subsections 'finding out what was wrong' and 'deciding the best treatment' for lung cancer. On the contrary, the latter two subsections were the least likely to be reported as positive by individuals reporting haematologic cancer. Finally, individuals with prostate and skin cancers were the least likely to report positive experiences for 'support for people with cancer', while individuals with prostate cancer were also the least likely to report positive experiences for 'home care and support'.

4 | DISCUSSION

This was the first large-scale measure of patient-reported experiences of cancer care in Switzerland using a validated questionnaire adapted to the Swiss context. Overall, experience with cancer care was rated rather highly. In particular, our results identified which areas of care were patient-centred, with over 80% of respondents reporting positive experiences with nurse consultations, diagnostic tests and inpatient care (e.g. confidence and trust in doctors; treated with respect and dignity and enough nurses). On the other hand, results showed where patient-centredness was suboptimal, with less than 60% of patients reporting positive experiences in relation to communication, information and supportive care issues, such as receiving written information at diagnosis, advice and support short- and long-term side

TABLE 2 Percentage of positive experience by evaluative question, overall and by type of cancer

Percentage of positive experience	n	All Cancers	Colorectal (n = 289)	Breast (n = 1105)	Prostate (n = 237)	Lung (n = 414)	Haematologic (n = 438)	Skin (n = 144)	p-value
Before seeing a specialist									
Q1. Seen as soon as necessary	2545	84.4	81.2	86.7	82.6	83.3	84.5	87.2	
Diagnostic tests									
Q2. Had all the information needed beforehand	2162	83.3	84.0	86.7	80.7	89.6	72.1	89.8	
Q3. Waiting time before the test thought to be right	2148	89.9	85.1	90.8	86.3	90.5	92.8	95.0	*
Q4. Test results explained in an understandable way	2151	80.9	82.0	81.4	78.5	83.3	77.1	79.2	
Finding out what was wrong									
Q5. Told they could bring family or friend beforehand	2435	48.9	46.3	46.9	45.9	55.1	52.9	39.2	*
Q6. Told they had cancer in a sensitive manner	2666	77.5	78.6	77.6	77.1	79.6	74.3	81.0	
Q7. Understood explanations of what was wrong	2729	74.2	74.9	74.9	78.2	79.6	64.4	75.4	**
Q8. Received written information about cancer that was easy to understand	1695	49.9	57.1	46.3	65.1	52.2	40.7	49.4	**
Deciding the best treatment									
Q9. Different types of treatment explained beforehand	2416	81.0	78.0	80.9	81.2	84.4	77.6	81.5	
Q10. Possible side-effects explained in an understandable way	2634	68.4	67.7	68.8	68.1	72.3	64.2	65.7	
Q11. Offered practical advice and support in dealing with side-effects	2280	57.7	58.6	59.7	52.1	63.4	54.1	42.4	**
Q12. Told about possible side-effects occurring in the future	2442	49.9	43.1	46.8	62.0	54.8	48.7	53.3	**
Q13. Involved as much as wanted to be in care decisions	2654	71.0	72.2	68.5	75.6	76.5	67.4	76.8	*
Consultation with specialist nurse									
Q14. Easy to contact nurse	1100	92.6	90.1	92.8	95.7	92.7	89.0	100.0	
Q15. Received understandable answers to important questions	1096	96.1	97.1	96.6	97.1	94.9	93.6	87.5	
Operations									
Q16. Had all the information needed beforehand	1045	85.0	82.8	82.2	92.2	90.4	84.0	88.0	
Q17. Operation results explained in an understandable way	1011	73.8	75.2	67.9	73.7	78.8	82.8	82.2	*

TABLE 2 (Continued)

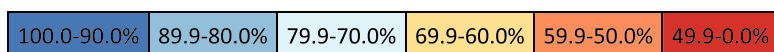
Percentage of positive experience	n	All Cancers	Colorectal (n = 289)	Breast (n = 1105)	Prostate (n = 237)	Lung (n = 414)	Haematologic (n = 438)	Skin (n = 144)	p-value
Hospital care as inpatient									
Q18. Doctors and nurses did not talk in front of patient as if they were not there	1077	84.7	77.6	91.3	86.1	77.7	84.7	81.0	**
Q19. Confidence and trust in all ward doctors	1080	82.6	84.3	83.8	86.4	76.5	82.8	87.3	
Q20. Patient's family had opportunity to talk to doctor	789	81.9	82.5	81.3	83.3	78.1	83.2	86.1	
Q21. Confidence and trust in all ward nurses	1082	77.8	76.5	77.3	84.0	73.3	81.5	81.0	
Q22. Always or nearly always enough nurses on duty	1074	87.3	84.8	88.6	90.1	81.9	92.9	83.9	
Q23. Always given enough privacy when discussing condition or treatment	1077	77.9	73.2	77.5	84.0	73.5	83.4	80.7	
Q24. Found someone on hospital staff to talk to about worries and fears	786	57.3	52.2	58.8	60.4	52.6	67.7	44.4	
Q25. Hospital staff did everything they could to help control pain	1011	84.5	82.8	83.8	84.9	83.0	88.4	89.5	
Q26. Always treated with respect and dignity by staff	1081	91.3	88.9	91.8	93.8	87.6	92.4	93.7	
Q27. Received written information about what they should (not) do post discharge	684	71.1	65.7	73.6	74.5	61.2	75.5	75.0	
Q28. Told by staff who to contact if worried post discharge	815	90.6	89.1	88.5	90.6	90.6	92.7	95.7	
Hospital care as day patient/outpatient									
Q29. Find someone on hospital staff to talk to about worries and fears	1156	70.9	69.1	69.8	71.3	74.0	78.0	58.6	
Q30. Doctor had the right notes and documents available	1293	85.7	86.7	80.5	84.9	92.2	88.8	86.1	**
Q31. Time spent in waiting room correct/quite correct	1444	78.8	80.6	78.9	86.5	76.6	85.4	62.5	**
Radiotherapy									
Q32. Had all the information needed beforehand	737	85.6	80.3	86.5	83.8	87.1	85.1	86.4	
Q33. Results explained in an understandable way	626	67.9	60.0	67.8	60.7	69.7	73.8	66.7	
Chemotherapy									
Q34. Had all the information needed beforehand	762	79.5	81.3	79.2	92.0	75.3	79.5	85.7	
Q35. Results explained in an understandable way	689	74.3	73.6	72.0	81.0	72.7	77.9	66.7	

(Continues)

TABLE 2 (Continued)

Percentage of positive experience	n	All Cancers	Colorectal (n = 289)	Breast (n = 1105)	Prostate (n = 237)	Lung (n = 414)	Haematologic (n = 438)	Skin (n = 144)	p-value
Home care and support									
Q36. Family given all information needed to help care at home	1914	57.5	64.8	51.2	57.5	60.5	60.9	62.8	*
Q37. Given enough care from health or social services during treatment	1767	58.0	66.5	58.1	52.7	51.7	57.0	64.1	
Q38. Given enough care from health or social services after treatment	1161	48.6	45.7	48.6	43.1	47.7	49.7	46.9	
Support for people with cancer									
Q39. Hospital staff gave information about support groups	1752	79.7	77.8	86.0	64.6	72.2	78.3	56.9	*
Q40. Hospital staff discussed or gave information on impact of cancer on daily activities	1556	76.2	76.0	77.0	76.3	75.9	78.7	59.4	
Q41. Hospital staff gave information on getting financial help or benefits	1304	48.6	38.2	55.4	38.4	38.8	52.5	33.3	*
Care from GP									
Q42. GP given enough information about patient's condition and treatment	2351	86.7	91.1	83.2	89.2	88.2	89.0	83.3	**
Q43. GP and staff did everything they could to support patient	1935	73.1	76.5	68.5	72.2	76.7	75.2	77.1	
Overall care									
Q44. People treating and caring for you worked well together	2655	62.0	68.0	55.7	69.5	64.3	65.0	62.2	*
Q45. Received a care plan	2096	36.5	41.1	37.3	37.8	34.7	34.4	27.7	
Q46. Administration of care rated as very good or good	2696	89.9	92.2	88.8	89.7	91.8	89.6	92.8	
Q47. Overall rating of care = 10/9/8	2696	83.0	84.3	79.7	85.2	85.7	84.5	89.9	*
Overall rating of care, mean (SD)	2696	8.54 (1.4)	8.60 (1.3)	8.40 (1.5)	8.53 (1.6)	8.63 (1.3)	8.63 (1.3)	8.75 (1.2)	##

Note: Pearson's χ^2 (or Fisher's) test * $p < 0.05$; ** $p < 0.01$; one-way ANOVA test ## $p < 0.01$; all p -values corrected for multiple testing. Colour-shading of the percentages of positive experiences:



effects, as well as information about social and financial support. We also found that experiences of care varied according to the type of cancer, without being systematically more positive (or negative) in all areas of care for one type of cancer.

Experiences around the communication of cancer diagnosis, especially regarding the receipt of written information and the

involvement of family or friends, were poorly rated by study participants. This was particularly the case in respondents with haematologic cancers, similarly to the findings of a recent systematic review covering mainly studies from Australia, the United States and Canada where a high prevalence of unmet informational needs was found in this population (Tsatsou et al., 2020). Communication around the cancer

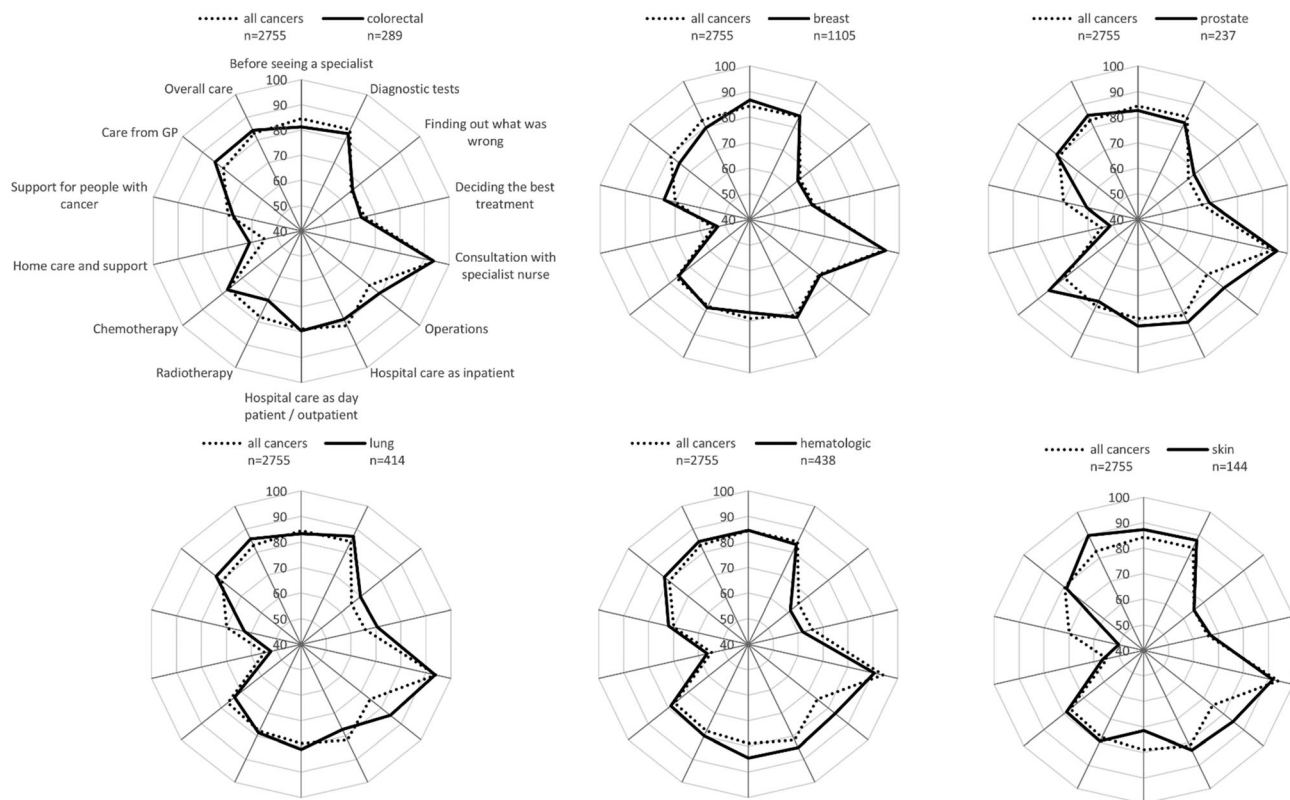


FIGURE 1 Positive experience score in the 14 subsections, overall and by type of cancer. Legend: all cancers: all respondents; colorectal: respondents reporting colorectal cancer; breast: respondents reporting breast cancer; prostate: respondents reporting prostate cancer; lung: respondents reporting lung cancer; haematologic: respondents reporting haematologic cancer; skin: respondents reporting skin cancer. Positive experience scores were calculated as the proportion of positive experiences in the questions of the subsection averaged across patients.

diagnosis is a key moment in the patient journey, which requires healthcare professionals to be responsive to each patient's individual needs making it a difficult exercise. Tailored information for each patient and his/her relatives remains a challenge to date, despite its important impact on quality of life, anxiety and depression (Husson et al., 2011). Cancer-specific information brochures intended for patients and published by the Swiss cancer league are available in the three national languages. However, our results suggest that these brochures might not be sufficient to ensure responsive care during the diagnostic phase; more tailored approaches are required to meet patients' needs.

Less positive experiences also concerned information and support on side effects during and after the treatment, especially for individuals diagnosed with colorectal and haematologic cancers. This is a frequently reported problem area in cancer care, as shown in studies in Germany in outpatient settings for instance (Kleeberg et al., 2008; Liekweg et al., 2005). The need for interventions to facilitate self-management of symptoms has been previously highlighted (Howell et al., 2021) and programmes are currently being implemented in Switzerland (Bana et al., 2020). To improve the management of symptoms and side effects, these programmes should be further developed, implemented and evaluated.

Within our surveyed population, we observed that experiences of care varied among patients with different cancer diagnoses, although

not consistently; better experiences were reported for different types of cancer at different times in the care pathway. As our analyses were adjusted for the main socio-demographic drivers of patient satisfaction (age, sex, health status, education and financial hardship), explanations for these patterns may be related to disease-specific factors, such as treatment burden and prognosis as suggested in previous studies, where patients with poor prognosis tend to report worse experiences of care for instance (Ayanian et al., 2010; Saunders et al., 2015). This finding suggests that improvement strategies should be tailored by type of cancer and care trajectory. These strategies should include the provision of information more easily understandable as well as emotional support for patients with diagnoses at higher risk of poorer experience. In our study, inpatient care for individuals with colorectal and lung cancer was consistently rated the lowest, suggesting that inpatient care for these patients would benefit the most from more patient-centred care responding to their specific needs. Lower ratings among colorectal patients were also often reported in previous studies (Bone et al., 2014; Clucas, 2016; Engel et al., 2018; Heerdegen et al., 2017; Sherlaw-Johnson et al., 2008). On the other hand, patients with breast cancer tended to report more often higher levels of positive experiences, as reported in most studies (Clucas, 2016; Davidson & Mills, 2005; Heerdegen et al., 2017; Pham, Gomez-Cano, et al., 2019; Saunders et al., 2015; Sherlaw-Johnson et al., 2008), though some also reported the contrary (Arraras

TABLE 3 Adjusted odds ratios (OR) of reporting a positive experience, by type of cancer

Adjusted OR of reporting a positive experience	n	Colorectal (n = 289)	Breast (n = 1105)	Prostate (n = 237)	Lung (n = 414)	Haematologic (n = 438)	Skin (n = 144)	p-value
Before seeing specialist								
Q1. Seen as soon as necessary	2285	Ref	2.00	0.90	1.27	1.45	1.57	
Diagnostic tests								
Q2. Had all the information needed beforehand	1938	Ref	1.13	0.93	2.24	0.87	1.84	
Q3. Waiting time before the test thought to be right	1926	Ref	1.87	1.08	1.88	2.15	2.91	*
Q4. Test results explained in an understandable way	1926	Ref	1.04	0.83	1.21	0.67	0.72	
Finding out what was wrong								
Q5. Told they could bring family or friend beforehand	2160	Ref	1.02	1.04	1.42	1.28	0.75	
Q6. Told they had cancer in a sensitive manner	2381	Ref	1.32	0.75	1.22	0.88	1.19	
Q7. Understood explanations of what was wrong	2431	Ref	1.30	0.99	1.56	0.64	1.06	**
Q8. Received written information about cancer that was easy to understand	1494	Ref	1.04	0.94	0.99	0.53	0.79	*
Deciding the best treatment								
Q9. Different types of treatment explained beforehand	2139	Ref	1.20	1.38	1.73	1.00	2.03	*
Q10. Possible side-effects explained in an understandable way	2347	Ref	1.19	1.06	1.57	0.92	1.06	
Q11. Offered practical advice and support in dealing with side-effects	2032	Ref	1.13	0.76	1.46	0.84	0.60	**
Q12. Told about possible side-effects occurring in the future	2177	Ref	1.41	2.29	1.76	1.30	1.77	*
Q13. Involved as much as wanted to be in care decisions	2368	Ref	0.95	1.08	1.60	0.89	1.27	*
Operations								
Q16. Had all the information needed beforehand	929	Ref	1.09	2.55	2.34	1.16	1.89	
Q17. Operation results explained in an understandable way	898	Ref	0.75	0.96	1.50	1.85	1.65	
Hospital care as inpatient								
Q18. Doctors and nurses did not talk in front of patient as if they were not there	949	Ref	2.58	1.53	1.19	1.60	0.94	
Q19. Confidence and trust in all ward doctors	951	Ref	1.57	0.82	0.68	0.89	1.33	
Q20. Patient's family had opportunity to talk to doctor	693	Ref	1.04	1.04	0.91	1.27	1.60	
Q21. Confidence and trust in all ward nurses	952	Ref	1.78	1.36	0.92	1.75	1.92	
Q22. Always or nearly always enough nurses on duty	905	Ref	1.70	1.09	0.96	2.39	0.93	
Q23. Always given enough privacy when discussing condition or treatment	948	Ref	1.88	1.46	1.20	2.44	1.48	

TABLE 3 (Continued)

Adjusted OR of reporting a positive experience	n	Colorectal (n = 289)	Breast (n = 1105)	Prostate (n = 237)	Lung (n = 414)	Haematologic (n = 438)	Skin (n = 144)	p-value
Q24. Found someone on hospital staff to talk to about worries and fears	690	Ref	1.27	1.23	1.17	2.18	0.84	
Q25. Hospital staff did everything they could to help control pain	885	Ref	1.41	0.85	1.23	1.75	1.81	
Q26. Always treated with respect and dignity by staff	911	Ref	2.37	1.36	1.16	2.14	2.10	
Q27. Received written information about what they should (not) do post discharge	601	Ref	2.56	1.10	1.04	1.83	1.65	
Q28. Told by staff who to contact if worried post discharge	793	Ref	0.93	1.43	1.49	2.05	2.38	
Hospital care as day patient/ outpatient								
Q29. Find someone on hospital staff to talk to about worries and fears	1022	Ref	1.01	1.19	1.79	1.76	0.85	
Q30. Doctor had the right notes and documents available	1157	Ref	0.76	0.92	2.48	1.40	1.29	*
Q31. Time spent in waiting room correct/quite correct	1287	Ref	1.05	1.29	0.99	1.64	0.47	*
Radiotherapy								
Q32. Had all the information needed beforehand	638	Ref	1.65	1.12	2.52	1.50	1.96	
Q33. Results explained in an understandable way	548	Ref	1.37	1.15	2.03	2.35	1.41	
Chemotherapy								
Q34. Had all the information needed beforehand	679	Ref	1.46	2.46	0.83	0.82	1.18	
Q35. Results explained in an understandable way	614	Ref	1.14	1.61	1.04	1.29	0.68	
Home care and support								
Q36. Family given all information needed to help care at home	1711	Ref	0.70	0.70	0.91	0.89	0.91	
Q37. Given enough care from health or social services during treatment	1561	Ref	0.81	0.54	0.60	0.76	0.92	
Q38. Given enough care from health or social services after treatment	1027	Ref	1.66	0.74	1.39	1.38	1.34	
Support for people with cancer								
Q39. Hospital staff gave information about support groups	1554	Ref	2.62	0.44	0.97	1.10	0.46	*
Q40. Hospital staff discussed or gave information on impact of cancer on daily activities	1390	Ref	1.56	0.91	1.33	1.28	0.47	*
Q41. Hospital staff gave information on getting financial help or benefits	1142	Ref	2.24	0.91	1.22	1.79	0.82	*
Care from GP								
Q42. GP given enough information about patient's condition and treatment	2094	Ref	0.76	0.60	1.07	1.07	0.72	
Q43. GP and staff did everything they could to support patient	1706	Ref	0.82	0.88	1.42	1.13	1.07	

(Continues)

TABLE 3 (Continued)

Adjusted OR of reporting a positive experience	<i>n</i>	Colorectal (<i>n</i> = 289)	Breast (<i>n</i> = 1105)	Prostate (<i>n</i> = 237)	Lung (<i>n</i> = 414)	Haematologic (<i>n</i> = 438)	Skin (<i>n</i> = 144)	<i>p</i> -value
Overall care								
Q44. People treating and caring for you worked well together	2367	Ref	0.82	0.92	0.98	1.01	0.88	
Q45. Received a care plan	1881	Ref	1.05	0.74	0.72	0.71	0.53	
Q46. Administration of care rated as very good or good	2410	Ref	0.98	0.52	1.14	0.70	1.11	
Q47. Overall rating of care = 10/9/8	2406	Ref	0.97	0.77	1.36	0.98	1.58	

Note: Adjusted for sex, age, education level, health status, financial hardship, and hospital. There were not enough individuals in the dichotomous response categories in the 'consultation with specialist nurse' section to perform adjusted analyses. ref: reference category; all *p*-values corrected for multiple testing **p* < 0.05; ***p* < 0.01.

Colour ranking: ranking from dark blue indicating 1st rank and highest OR (most likely to report positive experience) to dark red indicating 6th rank and lowest OR (least likely to report positive experience).

1 st rank = highest OR	2 nd rank	3 rd rank	4 th rank	5 th rank	6 th rank = lowest OR
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et al., 2013; Liekweg et al., 2005). These conflicting findings may be due to how care is organised and delivered. Breast cancer centres were among the first centres to be implemented in Switzerland, aiming at delivering comprehensive and coordinated cancer care. Breast cancer is also among the most researched type of cancer, receiving considerable amount of funding for improvement initiatives and support programmes as well as for the development and regular update of comprehensive evidence-based practice guidelines, all contributing to better care provided to women with breast cancer (Biganzoli et al., 2021; Carter & Nguyen, 2012). Implementation of cancer centres for other types of cancer, such as prostate and lung cancers, is more recent. This temporal lag and difference in availability of clinical practice guidelines might explain the difference regarding patient experience and warrants further investigation.

Our study adds useful information to the growing literature on patient experiences with cancer care reported in other countries such as the UK (Abel et al., 2014; Saunders et al., 2015), Denmark (Heerdegen et al., 2017; Sandager et al., 2015), Spain (Arraras et al., 2013), Canada (Coronado et al., 2017; Tremblay et al., 2015) and the United States (Ayanian et al., 2010; Lis et al., 2009), as well as on their use and usefulness to evaluate the quality of care delivery. Although our data reflect experiences with cancer care reported by patients treated within the Swiss healthcare system, they are quite similar to the results from cancer surveys conducted in other countries with different instruments. Indeed, issues related to communication and information, supportive care, or social and financial support, are often reported in patient experiences surveys as well as surveys on unmet needs (Harrison et al., 2009; Moghaddam et al., 2016). We can also compare our results to those published in England with the same instrument, despite differences in eligibility criteria (Gomez-Cano et al., 2020). While the mean rating of overall care (8.5) was slightly lower in our study compared with the mean rating reported in the yearly reports for the CPES national results [between 8.7 in 2015

and 8.8 in 2019 (NHS England, 2020)], the percentage of positive experiences followed a similar pattern in Switzerland and England, with the lowest scores reported in the 'home care and support' subsection. Rates differed notably for a few key questions when comparing results for 2018 in both countries: the rate of respondents reporting receiving written information at diagnosis, advice and support for side effects, and information on financial help was lower in our respondents (50% vs. 74%; 58% vs. 67%; and 49% vs. 60%, respectively). On the other hand, the percentage of patients reporting enough nurses on duty and support from GP was higher in Switzerland (87% vs. 67% and 73% vs. 59%, respectively). The interpretation of this international comparison is limited by many factors, but it allows us to put results in perspective and possibly investigate further reasons for the observed differences.

Our study had several strengths: It evaluated patient-reported experiences across the whole cancer care pathway using a cancer-specific validated questionnaire, evaluating key aspects of patient-centred cancer care in addition to overall satisfaction, in a relatively large sample of patients from university and regional hospitals. In addition, the variance observed in the participants' responses and limited number of items with a ceiling effect (>90%) can be interpreted as a methodological advantage of this experience survey in comparison to traditional satisfaction surveys. However, the results of our study should be interpreted with caution considering the following inherent limitations to survey data. Results reflect experiences of care from patients who responded to the survey. Indeed, previous studies have shown that survey respondents tend to be younger and of higher socio-economic background (Abel et al., 2016; Alessy et al., 2019; Nartey et al., 2020) compared with non-respondents, impacting representativeness of survey results and levels of reported satisfaction. In addition, surveys in cancer are surveys of survivors by design, excluding patients with short survivals (Lyrtatzopoulos et al., 2012; Nartey et al., 2020). Reaching patients who tend to not

respond to surveys can be achieved through different methods, such as qualitative interviews. Regarding cancer representativeness, compared with the distribution of incident cases available from the Federal Office of Statistics for the French- and Italian-speaking region of Switzerland (Federal Statistical Office [FSO], 2020), individuals reporting breast cancer were overrepresented in our sample, while individuals reporting prostate cancer were underrepresented. Finally, the eligibility criteria regarding the type of cancer was restricted to the six most frequent types for statistical and feasibility reasons, limiting the generalisation to other types of cancer. Based on the results of this study, a follow-up study was launched in 2021 among patients with any types of cancer to overcome this limitation.

5 | CONCLUSION

The consideration of patient experience is both important and necessary to evaluate and improve the responsiveness and quality of healthcare services, aiming to meet both the clinical and social needs of each individual patient. Our study demonstrates the feasibility of conducting a wide-scaled study of patient experiences in the Swiss cancer care setting and provides an overview of the responsiveness of cancer care according to a large sample of cancer patients in French-speaking Switzerland. Such information helps inform and guide future research and improvement initiatives at the hospital level, particularly targeting patients with specific cancers at higher risk of a less positive experience. The successful implementation of the survey also gave the impulse for a larger experience survey in Switzerland, encompassing hospitals in both the French- and German-speaking regions of Switzerland.

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DATA AVAILABILITY STATEMENT

Data are available from the corresponding author upon reasonable request or from Data@Unisanté, the institutional data repository under DDI Document ID 10.16909-DATASET-20.

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