ISSN: 3065-3630
Research Article

Journal of Clinical Nursing & Reports

Activation in Cancer Survivorship in Kenya: Results of A Cluster-Randomized Trial

Nebert K Mchidi[1*], John P Oyore[2] & Gordon Ogweno[3]

[1]*Kenyatta National Hospital, P.O Box 20723-00202, Nairobi –Kenya*
[2]*Department of Community Health and Epidemiology, School of Public Health, Kenyatta University P.O Box 43844-00100, Nairobi – Kenya*
[3]*Department of Medical Physiology, School of Medicine, Kenyatta University P.O Box 43844-00100, Nairobi – Kenya*

[*]Corresponding author: Nebert Mchidi, Kenyatta National Hospital, P.O Box 20723-00202, Nairobi –Kenya.

Submitted: 24 June 2024 **Accepted:** 02 July 2024 **Published:** 09 July 2024

https://doi.org/10.63620/MKJCNR.2023.1032

Citation: *Mchidi, N. K., Oyore, J. P., & Ogweno, G. (2024). Activation in Cancer Survivorship in Kenya: Results of A Cluster-Randomized Trial. J of Clin Nur Rep, 3(3), 01-07.*

Abstract

Introduction: *Kenya's cancer situation, as in the rest of the developing world, is marred by treatment access deficiencies arising from multiple foci in the continuum of health care that make survival difficult. These challenges, stemming from patient, service, and service provider points of view, place the patient at an increasing need for continuous support through the survivorship. This study, aimed at improving the patient's knowledge, skills, and confidence in self-care; and has been conceptualized as activation. Data on patient activation have demonstrated the positive influence of activation on different survivorship outcomes, including symptom management, adherence, and improved quality of life. In Kenya, there is a dearth of data on the utility of SMS interventions to shape patient activation, particularly for cancer.*

Methods: *This multisite study evaluated the effectiveness of mobile phone SMS support on patient activation among adult cancer patients in Kenya. Specifically, the study sought to determine the influence of individual factors and the intervention on patient activation. Data were collected using questionnaires. Ethical approval was obtained from the Kenyatta University Ethics Review Committee and various Hospital Ethics Review Boards. A permit to conduct the study was obtained from the National Commission for Science, Technology, and Innovation (NACOSTI), while consent was obtained from individual participants. A DSMB was formed to address any SAE of the study.*

Results: *The mean age of the participants was 52.9 ±12.9 years. Most of the participants reported delayed initiation of cancer treatment. Furthermore, the majority, 56.9% (n = 230), of the participants were activated in care. The majority of 95.7% (n-=220) of those activated in care were in the intervention arm and this was statistically significant (χ^2dd = 326.550, p=<0.001).*

Conclusions: *the SMS support intervention has shown superiority in influencing patient activation and several demographic factors have a significant influence on patient activation. There is a need to redesign the initiation of cancer treatment to prevent delayed initiation of treatment.*

Keywords: Activation, Cancer, Symptom Distress, Quality of Life, Short Message Service, Survival.

Introduction

Kenya's cancer burden mirrors the rest of the world, yet access to cancer treatment still stands at 28% and the quality of care offered to those who access it is still suboptimal due to a multiplicity of factors [1-3]. In Kenya, cancer is the third cause of mortality after infectious diseases and cardiovascular diseases, accounting for 7% of total national annual mortality, with an estimated annual incidence of approximately 42,116 cases,

an annual mortality of over 27,092 and a 5-year prevalence of 82,620 cases [4].

Kenya's commitment to mitigate cancer has glocalized policy directions through the Constitution, article 43a and the National Cancer Control Strategy (NCCS) [5]. The policy implications of these documents aim to harmonize and coordinate cancer care. The ambitious third pillar in the National Cancer Control Strategy seeks to ensure timely initiation of comprehensive treatment, strengthening access to sustainable quality care and improving the quality of life for cancer patients. This quest is ambitious in the context that Kenya has only 12 comprehensive cancer treatment centres and few cancer specialists.

The NCCS leans heavily on what cancer players, including the state, can do to address the cancer burden. This paternalistic approach creates the danger of overlooking the quality of cancer survivorship enshrined in the maxims of nothing about me without me [6, 7]. Specifically, cancer survivorship quality incorporates patient care, respect for the patient, patient activation, comfort, and advocacy [8, 9]. Cancer patient activation refers to the knowledge, skills, and confidence in self-management [10, 11]. Due to the ravenous and ruinous nature of cancer, cancer patients must be activated in care to promote and improve care outcomes throughout the continuum of cancer care continuum, and in varied contexts [12]. An activated patient is more likely to participate in self-care and promote treatment adherence.

There is an thrust of energy towards patient activation in cancer care, and evidence demonstrates a strong link between patient activation and adherence to treatment, which results in better self-reported and objective clinical outcomes for the patient [13, 14]. have demonstrated the utility of patient activation in chronic diseases, which enhances patient healing. If improved, patient activation can be the necessary component in achieving the 80% completion rate of treatment advocated in the NCCS [15]. Additionally, cancer survivorship interventions should use patient activation as a component of cancer care outcomes.

Materials and Methods

Study Design and Setting

This was a randomized trial in groups of two conducted in eight cancer treatment centers in Kenya. Kenyatta National Hospital, Jaramogi Oginga Odinga Teaching and Referral Hospital and Moi Teaching and Referral Hospital were randomly assigned to the intervention arm, while Kakamega County General Referral Hospital, Coast General Teaching and Referral Hospital, Machakos County Referral Hospital, Texas Cancer Centre, and M.P. Shah hospital were randomly assigned to the control arm.

Participants and Sample Size

The study was carried out among 404 outpatient participants who received intravenous chemotherapy in the eight (8) groups in Kenya.

The Intervention

The intervention was called SMS support and was designed to improve patient activation by using a mobile phone short message service to promote cancer and cancer self-care health literacy for cancer distress. Participants in the intervention arm received a two-part text message on (i) self-care for general cancer survivorship and (ii) keeping clinic appointments for scheduled chemotherapy. Those in the control arm received only a message about a reminder to keep clinic appointments for scheduled chemotherapy only. Text messages were sent to the participant's mobile phone every week from the start of chemotherapy treatment to the last chemotherapy cycle. At the end of the treatment cycles, participants were selected using simple random sampling strategies to answer questions regarding symptoms and patient activation.

Outcome Measure

The outcome variable, patient activation, was operationalized as the degree to which cancer patients rated the knowledge, skills, and confidence they had in self-management with respect to cancer13.

Data Collection

A questionnaire comprising of questions on individual factors, symptoms burden was used to collect data. Data on patient activation were collected using adaptions from the patient activation scale and the symptom distress scale [16-18]

Statistical Analysis

SPSS version 26 (IBM Inc.®) and SAS were used to descriptively analyze the data. The R program (v4.2.2) was used to calculate the adjusted chi-square test to determine the significance of the difference between categorical variables. A test with a value of $p < 0.05$ was considered statistically significant.

Ethical Considerations

The study was approved by the National Commission for Science Technology and Innovation (NACOSTI) and the hospital ERBs in all eight groups (see attachments). A DSMB was set up to assess the magnitude of any SAE directly resulting from the study. Participants consented to enroll and selected to answer questions about various aspects of cancer care they received in treatment facilities. Data safety was ascertained according to the Health Insurance Portability and Accountability Act (HIPPA) 006. Permission to send educational text messages was granted by relevant government authorities.

Results

Respondent Characteristics

The mean age of the study participants was 52.9 ±12.9 years. Described in terms of the national stratification for age espoused in the Senate act, (2020), the majority 70.8%, (n= 286) were young. The majority, 68.1% (n = 275), of the participants were female, 75.5% (n=305) were married, 47.3% (n = 191) were primary school students, 53.2% (n=215), reported being in the lower financial freedom category, and 66.6% (n = 269) were not employed [19]. The results show that more than 2/3 of the respondents started chemotherapy treatment after 2 months of definitive diagnosis. These results are shown in Table 1.

Table 1: Demographic and Descriptive Characteristics of the Respondents.

Characteristic		Frequency (%)	
Age	Young	286	70.8
	Old	118	29.2
Gender	Female	275	68.1
	Male	129	31.9
Marital status	Married	305	75.5
	Single	46	11.4
	Other	53	13.1
Treatment initiation after Diagnosis	> 2 months	243	60.1
	< 2 months	161	39.9
SMS satisfaction	No	113	28
	Yes	291	72
Facility	Public	334	82.7
	Private	70	17.3
Employment status	Not employed	269	66.6
	Employed	135	33.4
Education level	Tertiary	80	19.8
	Secondary	133	32.9
	Primary	191	47.3
Financial wellness	Low	215	53.2
	High	189	46.8

Symptom Burden

The experience of cancer symptoms was assessed on a 7-day recall using the symptom distress scale 11,12. The results shown in Table 2 show that the majority of the respondents, 54.2% (n=219) reported having experienced normal appetite within the recall period. Furthermore, 50.7% (n=205) reported experiencing pain most of the time in the recall period. The majority of the respondents, 53.5% (n = 216), reported being unable to adequately manage pain. Further results show that the majority of respondents experienced depressed mood and xerostomia. These results are shown in Table 2 below.

Table 2: Symptom Distress Results

Characteristic		Frequency (%)	
Appetite	Normal	219	54.2
	Poor	185	45.8
Sleep	Normal	226	55.9
	Disturbed	178	44.1
Pain experience	Sometimes	199	49.3
	Most of the time	205	50.7
Pain management ability	Yes	188	46.5
	No	216	53.5
Energy levels	Normal	237	58.7
	Tired	167	41.3
Constipation experience	No	164	40.6
	Yes	240	59.4
Diarrhoea experience	No	176	43.6
	Yes	228	56.4
Mood	Euthymia	183	45.3
	Depressed mood	221	54.7
Dry mouth experience	No	163	40.3
	Yes	241	59.7

Patient Activation

The modified patient activation scale assessed participants' perceived confidence in managing their symptoms after completing chemotherapy treatment. From the findings, the majority, 47.5% (n=192) of the participants, were very confident that they were able to maintain healthy lifestyle changes they had adopted, 41.6% (n=168) knew how to prevent future health problems and 48.0% (n=194) were confident that they could maintain lifestyle changes such as diet and exercise even during times of stress respectively as shown in Table 3 below.

Table 3: Patient Activation

Characteristic	Frequency (%)			
	Not at all	A little bit	Quite a bit	Extremely
I have learnt how to maintain the lifestyle changes for my health.	74 (18.3)	60 (14.9)	78 (19.3)	192 (47.5)
I now know how to prevent further problems with my cancer condition.	56 (13.9)	65 (16.1)	115 (28.5)	168 (41.6)
I am confident that I can maintain lifestyle changes, such as diet, even during times of stress.	56 (13.9)	58 (14.4)	96 (23.8)	194 (48.0)

The patient activation scale scores were summed for each participant and dichotomized into activated or not activated using the median score as the lower limit. The majority, 56.9% (n=230) of the participants were activated in care Figure 1.

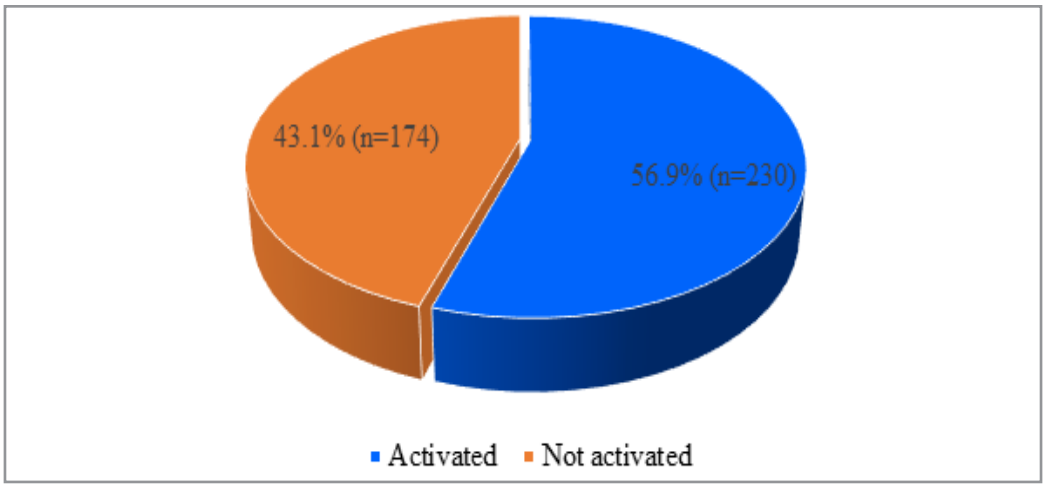

Figure 1: Proportion of Participants who were Activated

Influence of Demographic Factors on Patient Activation

The results of the study show that age (χ^2dd = 4.710, p=<0.030), employment (χ^2dd = 17.889, p=<0.001), and education level (χ^2dd = 16.522, p=<0.001) were significant in explaining the differences in activation among the participants. Although not significant, the results show that the female participants were found to be more activated than the male participants (χ^2dd = 0.304, p=0.581). These results are shown in Table 4 below.

Table 4: Demographic Characteristics Influence on Patient Activation

Characteristic	Total	Patient activation in Cancer Care.		χ^2dd	Sig.
	N=404	Not Activated	Activated		
Age					
> 60 years	286 (70.8)	133(76.4)	153(66.5)		
< 60 years	1118(29.2)	41 (23.6)	77 (33.5)	4.710	0.030
Gender					
Female	275 (68.1)	121(69.5)	154(67.0)		
Male	129 (31.9)	53 (30.5)	76 (37.0)	0.304	0.581
Marital Status					
Married	305 (75.5)	124(71.3)	181(78.7)		

Single	46 (11.4)	20(11.5)	26(11.3)	
Other	53(13.1)	30(17.2)	23(13.1)	4.687 0.096
Treatment Initiation.				
> 60 days	243 (60.1)	114 (65.5)	129(56.1)	
< 60 days	161 (39.9)	60(34.5)	101 (43.9)	3.675 0.055
Employment status				
Yes.	269 (66.6)	96(55.2)	173(75.2)	
No.	135 (44.8)	78(44.8)	57(24.8)	17.889 <0.001
Educational level				
Primary	80(19.8)	49 (65.4)	31(34.6)	
Secondary	133 (32.9)	59 (43.1)	74 (56.9)	
Tertiary	191(47.3)	66(37.5)	125(54.3)	16.522 <0.001

Influence of Symptom Experience on Patient Activation

The results of the adjusted chi-square analysis and patient activation are shown in Table 5 below. The results show that the participants who were activated reported experiencing normal appetite during the recall period (χ^2dd = 184.316, p=<0.001). Although pain was experienced in those who were activated, the results show a better agreement on pain management skills among those who were activated than among those who were not activated (χ^2dd = 122.606, p=<0.001). Regarding mood, most of those in the activated group reported euthermic mood, a result that was statistically significant.

Table 5: Chi-square Analysis of Activation and Symptom Distress Measures

Characteristic	Total	Patient activation in Cancer Care.		χ^2dd Sig.
	N=404	Not Activated	Activated	
Appetite				
Normal	219 (54.2)	27 (15.5)	192(83.5)	
Poor	185 (45.8)	147 (84.5)	38 (16.5)	184.316 <0.001
Sleep				
Normal	226 (55.9)	42 (24.1)	184 (80.0)	
Disturbed	178 (44.1)	132 (75.9)	46 (20.0)	125.419 <0.001
Experienced pain				
No	199 (49.3)	34 (19.5)	165(71.7)	
Yes	205 (50.7)	140 (80.5)	65 (28.3)	107.988 <0.001
Able to manage pain.				
Yes.	188 (46.5)	26 (18.9)	162(70.4)	
No	216 (53.5)	148 (85.1)	68 (29.6)	122.606 <0.001
Experienced fatigue				
Yes.	237 (58.7)	41 (23.6)	196 (85.2)	
No.	167 (41.3)	133 (74.6)	34 (14.8)	155.281 <0.001
Experienced constipation				
Yes.	240 (59.4)	157 (65.4)	83(34.6)	
No.	164 (40.6)	17 (43.1)	147(56.9)	120.417 <0.001
Experienced diarrhoea				
Yes.	228 (56.4)	145 (63.6)	83 (36.4)	
No.	176 (43.6)	29 (16.5)	147 (83.5)	89.939 <0.001
Mood				
Euthymic.	183 (45.3)	25 (13.7)	158 (86.3)	
Depressed.	221(54.7)	149 (67.4)	72 (32.6)	119.994 <0.001
Dryness of mouth.				
No.	163 (47.8)	24 (14.7)	139(85.3)	
Yes.	241 (52.2)	150 (62.2)	91 (37.8)	6.222 0.013

Influence of SMS Support on Patient Activation

The results show that the intervention was significant in influencing patient activation, with the majority of those who were activated in the intervention arm of the study as shown in Table 6.

Table 6: Chi-square Results of The Influence of Intervention on Patient Activation

Characteristic	Total	Patient activation in Cancer Care.		χ^2dd Sig.
	N=404	Not Activated	Activated	
Arm of Study				
Intervention	230 (56.9)	10 (5.7)	220(95.7)	
Control	174 (43.1)	164 (94.3)	10 (4.3)	326.550 <0.001

Discussion

A cancer diagnosis is overwhelming and patients are often overwhelmed with information that cloud their judgment, hence the need to continuously educate them about cancer and its treatment side effects and general well-being to improve cancer treatment outcomes A cancer patient who demonstrates greater control over, and has the ability to strive for wellness in tandem with the dictates of health promotion, is considered activated [20].

Patient activation is influenced by many demographic factors. The findings of this study show that being older than 60 years, being married and having lower education are associated with increased patient activation. This finding is however antipodes to, who found that activation was better in those with higher education and incomes, although the severity of cancer in this study is different from that of arthritis [21].

In Kenya, the risk of developing cancer is higher in females that males, and reflects the disproportionately higher prevalence of women in this study Furthermore, the results show that many cancer patients in Kenya delay the start of treatment and a multiplicity of factors may be at play for this observation. First, treatment initiation delays can be attributed to the NHIF requirement that any defaulted payment or a new member must wait 60 days before the card is active. Second, the results show that 66.6 % and 53.2% of the respondents were not employed and reported being the low financial category group, respectively, reinforcing the negative correlation between finances and access to cancer management. It is not clear from the findings whether the low finances experienced by most is as a result of cancers financial toxicity34 or a generally a demographic attribute of cancer patients in Kenya.

Cancer care is complex and multifaceted, requiring caution when determining the causality of any intervention that may seem to work. Despite this reality, the field of activation interventions is growing, and no single intervention appears to be effective in all settings31. In general, the literature is rich in evidence that various interventions influence patient activation in cancer [22]. has shown that activation enhancing tools are important in mitigating cancer related side effects through patient education [23]. Further support for the utility of interventions to promote activation is by works of24, who, in a cluster randomized trial, found that patients who received home nursing care provided by a community health nurse (CHN) reported a lower number of emergency visits, lower utilization of health care, and lower admission rates in the intervention group compared to the control group that received usual treatment.

In this study, SMS Support was designed to improve participant health literacy related to cancer and cancer treatment through structured education delivered by SMS. mobile phone. The results of this study show that the participants in the intervention were more activated than those in the control. Improved health literacy in the intervention may explain the increased preponderance of initiating and maintaining positive health and wellness behavior in this group. This finding agrees with, who reported that activated patients were 4.5 times more likely to cope with chemotherapy side effects than less activated patients, who were less likely to understand their diagnosis, follow treatment regimens, and be satisfied with their care. Furthermore, the positive consequence of activation in better treatment outcomes has been reported by who found that patients who were activated had confidence in the treatment of fatigue, nausea and diarrhoea and were more adherent to oral oncolytics Moreover, underscored the influence of patient activation on the promotion of adherence to cancer treatment and have suggested that cancer interventions should involve the input of self-management interventions by informal caregivers. has demonstrated the value of caregiver activation [24]. In this study, Bakker's view is supported by the fact that participants who were unable to read text messages were read by a support person, who invariably became educated about cancer and its treatment [25-27].

Conclusion

In conclusion, the results of the study show that SMS support is superior in shaping and influencing patient activation in Kenya. Additionally, the results show that various demographic factors, although not modifiable, are important in shaping patient activation and may be important reference points when designing policies on shaping patient activation in cancer care in Kenya. Furthermore, there is an urgent need to redesign cancer care financing and cancer model care link in line with the care link that has been found useful in HIV by breaking the financial barriers to cancer care link.

Declaration of Conflict of Interest

The authors declare that they have no conflict of interest in the conceptualization, design, implementation, and reporting of data related to this study.

Funding

The funding for this study was 100% from the PI and no external funding was sought, accessed or offered.

References

1. Boyle, P., Ngoma, T., Sullivan, R., Ndlovu, N., Autier, P., Stefan, C., ... & Brawley, O. W. (2016). The state of oncology in Africa 2015 (Vol. 1, p. 560). International Prevention Research Institute.
2. Sharma, R., Nanda, M., Fronterre, C., Sewagudde, P., Ssentongo, A. E., Yenney, K., ... & Ssentongo, P. (2022). Mapping cancer in Africa: A comprehensive and comparable characterization of 34 cancer types using estimates from GLOBOCAN 2020. Frontiers in Public Health, 10, 839835. https://doi.org/10.3389/fpubh.2022.839835
3. Ministry of Health Kenya. (2013). National palliative care guidelines.
4. Ministry of Health Kenya. (2023). The national cancer control strategy.
5. Laws of Kenya. (2013). The Constitution of Kenya: 2010. Chief Registrar of the Judiciary.
6. Dang, S. (2018). Shared decision making—the pinnacle of patient-centered care. Journal of the Indian Academy of Geriatrics, 14.
7. Institute of Medicine (U.S.). (2001). Crossing the quality chasm: A new health system for the 21st century. National Academy Press.
8. McCormack, B., McCance, T., Bulley, C., Brown, D., McMillan, A., & Martin, S. (Eds.). (2021). Fundamentals of person-centred healthcare practice. John Wiley & Sons.
9. Suhonen, R., Lahtinen, K., Stolt, M., Pasanen, M., & Lemetti, T. (2021). Validation of the patient-centred care competency scale instrument for Finnish nurses. Journal of Personalized Medicine, 11(6), 583. https://doi.org/10.3390/jpm11060583
10. Acquati, C., Hibbard, J. H., Miller-Sonet, E., Zhang, A., & Ionescu, E. (2022). Patient activation and treatment decision-making in the context of cancer: Examining the contribution of informal caregivers' involvement. Journal of Cancer Survivorship, 16, 929–939. https://doi.org/10.1007/s11764-021-01079-9
11. Hibbard, J. H., Mahoney, E., & Sonet, E. (2017). Does patient activation level affect the cancer patient journey? Patient Education and Counseling, 100(7), 1276–1279.
12. Yarbro, C. H., Wujcik, D., & Gobel, B. H. (2018). Cancer nursing: Principles and practice (8th ed.). Jones & Bartlett Learning.
13. Grover, S., Fitzpatrick, A., Azim, F. T., Ariza-Vega, P., Bellwood, P., ... & Sloan, D. A. (2022). Defining and implementing patient-centered care: An umbrella review. Patient Education and Counseling, 105(7), 1679–1688.
14. Hernar, I., Graue, M., Igland, J., Richards, D. A., & Riise, H. K. R. (2023). Patient activation in adults attending appointments in general practice: A cross-sectional study. BMC Primary Care, 24, 144.
15. Salgado, T. M., Mackler, E., Severson, J. A., Lindsay, J., & Batra, P. (2017). The relationship between patient activation, confidence to self-manage side effects, and adherence to oral oncolytic: A pilot study with Michigan oncology practices. Supportive Care in Cancer, 25, 1797–1807.
16. Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. Journal of General Internal Medicine, 27, 520–526.
17. Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Services Research, 39, 1005–1026.
18. McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. Cancer Nursing, 1, 373–378.
19. Senate of Kenya. (2020). Care and Protection of Older Members of Society Bill, Senate Bill No. 24. http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2020/TheCareandProtectionofOlder_MembersofSocietyBill_2020.pdf
20. World Health Organization. (2021). Health promotion glossary of terms.
21. Almalag, H. M., Alshehri, M. M., Altokhais, N. A., Aljanobi, G. A., Dessougi, M. I. E., ... & Alenzi, M. (2023). Exploring factors influencing patient activation in Saudi rheumatoid arthritis patients: A nationwide cross-sectional survey—Results from the COPARA study. Immunity, Inflammation and Disease, 11, 1101. https://doi.org/10.1002/iid3.794
22. Kanu, C., Brown, C. M., Rascati, K., Moczygemba, L. R., Mackert, M., ... & Novak, L. (2021). Are health literacy and patient activation related to health outcomes in breast cancer patients? HLRP: Health Literacy Research and Practice, 5(4), e253–e260.
23. Kimiafar, K., Mousavi, A. S., Baigi, S. F. M., Dahmardeh, F., & Layen, G. S. (2022). Effect of mobile health interventions for side effects management in patients undergoing radiotherapy: A systematic review. Journal of Cancer Research and Therapeutics, 14.
24. Bakker, E. M., Witkamp, F. E., Luu, K. L. N., Van Dongen, S. I., & Raijmakers, N. J. H. (2022). Caregiver activation of relatives of patients with advanced cancer. European Journal of Cancer Care, 31, e13656.
25. Agarwal, P., Gordon, D., Griffith, J., Kithulegoda, N., & Witteman, H. O. (2021). Assessing the quality of mobile applications in chronic disease management: A scoping review. NPJ Digital Medicine, 4, 46.
26. Donabedian, A. (2005). Evaluating the quality of medical care. The Milbank Quarterly, 83, 691–729.
27. Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., ... & Bray, F. (2021). Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA: A Cancer Journal for Clinicians, 71(3), 209–249.