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Assessment of Major Problems Expressed by Cancer Patients during Follow Up for Cancer Disease in COVID-19 Pandemic Period: A Cross Sectional Study

Dr. Aroop Roy Burman,
Radiation Oncologist, ABVRCC, Agartala, India
&
Dr. Bitan Sengupta,
District Surveillance Officer, South Tripura, India

Abstract: COVID-19 has hit almost all domains of our lives, including cancer care. Cancer care is the continuous process of maintaining the healthy, stable, and good quality of life of a cancer patient. Such an endeavor always needs good follow-up and maintenance of effective connectivity with the patients and their care-givers. For better and more successful patient care, resources are to be made available as per need, and such needs can be best understood by maintaining communication with the patients or their care givers. In the present study, patients and their care givers were inquired by using a pre-framed questionnaire to find out the problems for cancer patients on follow-up during the COVID-19 pandemic. The suspension of regular transportation, which is one of the most important cornerstones of COVID-19 pandemic control, was discovered to be a major problem for cancer patients on follow-up, and this scarcity of regular vehicles, in turn, increased the financial burden of the patients and their caregivers to continue follow-up. As a result of this information, follow-up may be reallocated and decentralized to locations near the patients' residences whenever possible. Two more things were also learnt: most of the patients included in the study have accessibility to mobile phones, and they are interested in discussing physical problems.

Keywords: Covid 19 problems, Cancer Communication, Corona challenges, Cancer follow up, Corona & Cancer, Cancer & mobile

Introduction:

Cancer is a disease with multi-dimensional problems. On the one hand, cancer patients need highly sophisticated care like radiotherapy, chemotherapy, or surgery from the tertiary cancer centers. On the other hand, most cancer patients, especially when the disease is in an advanced stage, need supportive care rather than strong, highly targeted curative treatment. The term coined for such supportive and symptomatic care is "palliative care" **(WHO, 2020).**Palliative care, by definition, is integrated, meaningful care provided to patients suffering from significant health-related problems, which may include physical, psychological, spiritual, or social symptoms. In cancer, such care is very significant and essential for patients with advanced stage disease and also for those with less disease burden. To provide equal reach to the palliative care facilities, it is being attempted to integrate them with the primary health care system with good capacity building and technical support. **F.R. Betty (2017)**It was also observed that the early deployment of palliative care improved quality of life and brought other positive changes in the patients when compared with those who got only standard care. Survival also became longer in patients who received palliative care **(Temel J S, 2010)**.

Whatever may be the name, the basic requirement for everyday care of a cancer patient needs to be attentive communication and the diffusion of essential and relevant health messages. Such action is never completed without good, sustained, and effective follow up. The role of communication in

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cancer is complicated and multifaceted. With the situation, the communication strategies change and the overall impression may be very different than what is commonly expected. Communication-related issues were discussed in detail in various articles. Anyway, communication needs frequent exposure with the patients and their care givers. **(Thorne S, 2013).**Conventionally, cancer hospitals are grown as separate entities and most of the tertiary centers are outfitted with sophisticated equipment, mostly for radical treatment. Of course, presently, many big centre's have developed symptomatic and supportive care areas where improvement in quality of life is the major issue. Anyway, such a pattern of care does not emphasize high-tech interventions by using costly machines but provides a solution to the basic troubles of the patients. It is most important to mention here that a patient who is on curative care should also receive palliative or symptomatic care simultaneously, and the latter care can be provided in almost all health institutions, including tertiary centers. The National Cancer Institute described unambiguously palliative care in cancer **(NCI, 2017)**. It is mentioned that a healthcare provider with special structured training on palliative care should render such services either individually or as a member of a multidisciplinary care giver panel. Additionally, the team or individual also needs to be well aware of the main oncological treatment modules. Palliative care for a cancer patient should address not only physical complaints but also entertain social, emotional, and spiritual matters. It should also take care of the family or friends of the patient who are actually concerned about the patient. Palliative care should be coordinated among the various sections of cancer health professionals taking care of a particular patient by mandatorily coordinating expert communication among different teams. It is also mentioned that palliative care should be started since the diagnosis of cancer and curative interventions should go hand in hand with palliative care.

From the fact sheet **(NCI, 2017),** it is clear that cancer patients should always remain in touch with their health institutions and should attend the outpatient department as well as the emergency wing if necessary, of the health institution periodically, even if they feel that they are apparently healthy. This means that travel for cancer patients is inevitable. During the COVID-19 Pandemic, to prevent the spread of the virus, several non-conventional and uncommon steps were executed worldwide. These preventive measures touch most of the aspects of our lives, including health care providing areas. Several changes were made in the health care delivery system, such as rescheduling hospital visits, converting real communication to virtual communication, self-isolation, suspension of regular tours and travel, and so on. Several international organizations addressed the issue of cancer patients traveling for follow-up care. One of them is the European Society for Medical Oncology (ESMO). A guideline for cancer patients needing travel is described by the European Society for Medical Oncology **(ESMO, 2020)**. It is opined that in the context of the COVID-19 pandemic situation, the necessity of concern has to be compared with the impending danger of COVID-19 infection. Hospital appointments may be seen as unavoidable, may be relocated after by telephonic conversation and placed at a nearby health institution, or may be delayed. It is clear that even as per this guideline, some patients will need to travel to higher centers for treatment. Anyway, the traveling distance may be reduced in some patients by careful selection of cases and referring them to nearby, well-equipped health institutions where trained palliative care services are also available. Telephonic communication appears to be a very useful technique for making wise decisions regarding cancer patients' travel-related matters on follow-up.By having a good telephone conversation with the patient and their caregivers, services for some patients may be made available at their door step by home visits. The role of skilled case-to-case communication always seems to be essential as many patients may be transferred to local health institutions instead of being subjected to long distance travel. Communication should bring coordination and end up in a good, helpful, and positive outcome.

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The standard preventive protocol for the prevention of the spread of COVID-19 viruses includes many measures. Avoiding gatherings is one of the most important techniques for stopping virus spread. Suspension of regular vehicle movement is undertaken to discourage travel and prevent crowds. Patients attending tertiary centers may assemble in large numbers, which may be sufficient to spread the virus among the patients who are otherwise very vulnerable to the disease. A study **(Jazieh A. R., 2020)** recently showed the problems of cancer patients during the COVID-19 period. The study was done with a web-based questionnaire, which was cross-sectional and included 51 items. The study was conducted from April 21 to May 8, 2020. The sample patient population expressed that due to disruption of care, both cancer-pertinent and non-cancer-associated services, there was significant damage to the patients. For cancer-relevant care, it was 36.52% and for non-cancer care, it was 39.04% and in some institutions, damage occurred even up to 80%. It was concluded in the study that COVID-19 has very strong and powerful detrimental effects on cancer care and considerably damages cancer patients, and hence, further studies are essential in this context. As already discussed, cancer patients are essentially in need of regular follow-up and, for that matter; many of them need to attend hospitals even during the COVID-19 Pandemic for various treatment-related matters. So, it is essential to know the problems patients are facing in order to maintain their appointment schedules so that proper anticipatory, preventive, and precautionary steps can be taken to save the cancer patients from harm. But very few studies focused directly on the problems of cancer patients on follow-up. In the present study, direct communication with cancer patients and their care givers was made, and self-declared statements were collected to learn about the difficulties they are facing during follow-up, with the aim that such information will guide the medicos in planning and reshuffling resources for the cancer patients on follow-up so that their interests are protected.

Methodology:

This cross sectional survey was conducted using prepared questionnaire among the cancer patients of a Tertiary Cancer Center (ABVRCC) of Agartala, a city in North East India.

Sample size was determined by considering average number of patients coming for follow up in the Cancer Center of a particular unit as 50 per day and monthly around 1000. It was assumed that around 50% may face some problem. The sample size was calculated by the formula $4pq / L^2$ with adjustment for finite population, confidence interval of 95% and 5% absolute error. The calculated sample size is found to be 277 (rounded to 300). Convenient samples were selected considering the willingness and capabilities to answer the questionnaire.

The questions were selected after some discussion with the patients and care givers who are not included in the sample and also with the health care givers of the institute. The answers were made easily understandable, most relevant and with no double meaning and validated after using them among above mentioned people.

Results and Analysis:

During the study, enquiry was made about possession and accessibility of android or touch phone capable of video calling. Result showed that only 18% patients possessed such phone. But 84% people told that they can access such phones capable of both audio-video calling. The usual source of such phones, as told by the patients or their family members was from the other family members. Further questioning revealed that only 11% of the patients were capable of operating fully audio & video mode. Rest of the patients was dependent on their expert family members for phone operation. Anyway, android phones were accessible at least in the family and could be used time to time on hiring basis.

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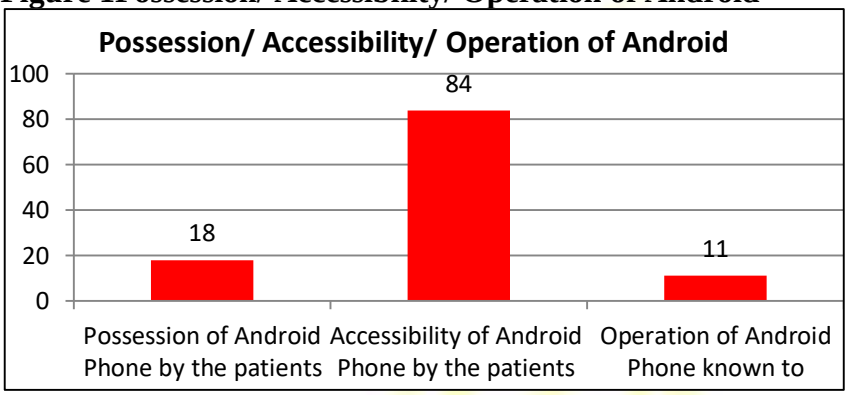
Table 1Possession / Accessibility of android / touch phone/ phones with audio-video call capacity

	Yes %	No %
Possession of Android Phone by the patients	18	82
Accessibility of Android Phone by the patients	84	16
Operation of Android Phone known to	11	89

Figure 1Possession/ Accessibility/ Operation of Android



This result gives a scope to the health workers to communicate with the patients over telephone and guide them appropriately. As mentioned earlier that ESMO **(ESMO, 2020)** also stressed on telephonic conversation with the patients and their care giver so that the hospital appointments can be reviewed as per urgency and can be postponed/ cancelled or redirected to other nearby health institution. This will minimize the travel distance and preventive protocols for Covid 19 can be followed more stringently. Scope for video communication may enhance the success of discussion at least in certain cases.

In a review article (Richards R, 2018)it has been shown that many cancer patients understood that mobile phone could be used as a very useful media for diffusion of many health related issues distantly. Side by side, mobile devices can be used for symptom supervising procedure so that communication which is pertaining to treatment can be passed to the patients. Such endeavor has the capacity to develop self-administration skills of the patient and also health workers can learn more about the problems of the patients along with building up of good rapport with the patients. Treatment related toxicities and earlier interference can be done properly and quality of life of the patients can be improved with good economic advantages. Till date, as per the article, the high potentiality of the mobile phone is not well explored and mostly few aspects of communication like coping skills etc done for cancer patients though much individualist information are required by the patients when they are away from their care givers. The demand for health messages varies in quality and quantity depending on the situation of the patient. Existing helpline, websites etc useful may be intermingled with the personal mobile network. So, it is necessary to understand that from the end of patients' and their care givers there are many issues which should be appreciated and need to be addressed. In the present study it is found that most of the persons included in the study have at least access to the mobile phone, though they personally cannot operate such devices. This information may guide us for further strengthening of health care delivery system.

Information was collected about the major problems faced by the patients and their care givers during follow up of cancer patients in Covid 19 Pandemic period. Closed ended questions touching various possible problems were asked during interview. The session became interactive. But the

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answers were collected as per the questions framed.

Various closed ended questions included many issues and nine topics touched. A point was kept open by asking any other problems beyond those framed. Problems related to emergency or routine care, non-availability of human resources in family-friends and Health care provider, movement problems related to Covid 19 regulations, any problem related to gender were asked. The issue of transport of patient and scarcity of the vehicle led to raise trouble in financial areas got the priority and 98% people complained of transport problems and almost similar number of (85%) people mentioned financial troubles due to the former. The table below shows the data in percentage.

Table 2 Problems during COVID 19 period in percent (%)

Problems during COVID 19 period in percent (%)		
1.	Transport	98
2.	Financial	85
3.	Emergency care	15
4.	Routine care	11
5.	Covid regulations	5
6.	Uncertainty about movement	0
7.	Human resource non-availability	22
8.	Health care giver shortage	2
9.	Gender related problems	0
10.	Others	0

Difficulties to get human resources among the close relatives or friends for helping in treatment was mentioned by 22% people, difficulties to appear for emergency care and routine care were mentioned by 15% & 11% people. Covid 19 regulations were not a major problem for most of the patients and family members interviewed and only 5% people mentioned these as a problem. Similarly, Health care giver shortage was also mentioned only by negligible number by patients (2%).

Role of self-reporting by the patients on treatment about worsening symptoms was assessed in a randomized control trail (Basch E, 2015). Cancer patients, very often, suffer from various symptoms which remain undiscoverable during conventional visits. But knowing such symptoms give scope to modify the treatment planning and give over all good symptom alleviation and overall compliance to the treatment. Hence, communication about various problems is necessary, justified and have role in providing better health care to the cancer patients. The information collected from patients directly should get due importance as these may reflect the ground reality. This study states that self-reporting of cancer patients about their problems is meaningful, useful and capable of influencing cancer care.

In another study (Tashkandi E, 2020) it is opined by 80% Oncologist that continuation of some treatments like adjuvant, neo-adjuvant and peri-operative for the cancer patients is evitable and need to be continued and 53% wanted to continue first line palliative treatment. This means cancer patients, in most of the cases, will need to travel certain distance and vulnerable to face travel associated problems.

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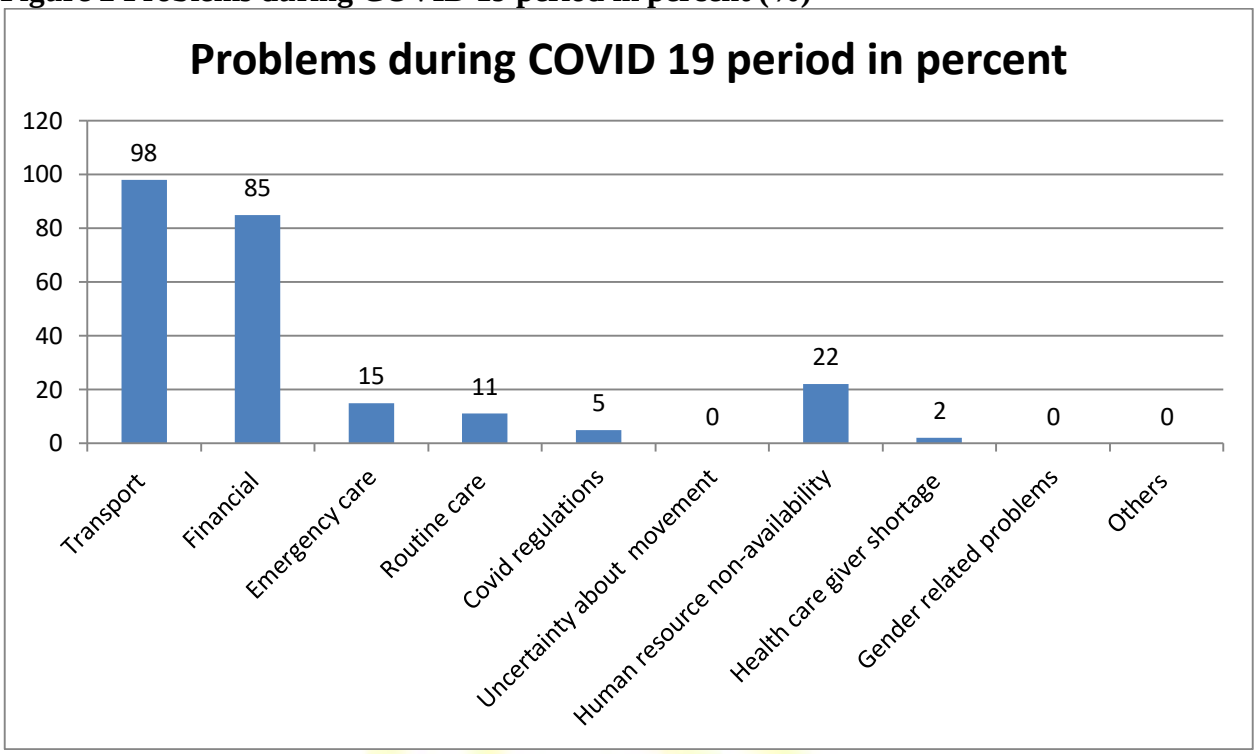
Figure 2 Problems during COVID 19 period in percent (%)



Issue of expenses in transport for a cancer patient is addressed in earlier time also. An article (Guidry J J, 1998) a cross sectional survey was described where hurdles of cancer care in Texas evaluated. It was reported that indirect barriers like transportation and straight forward expenses like cost of care etc gave strong obstacle in cancer treatment. It is opined that such barriers are to be addressed routinely by the cancer care givers and is to be solved by the treating agencies. In present study also it is seen that most of people complained about scarcity of transportation leading to higher payment for bringing the patient in the tertiary care center. This problem increased the expenses of cancer care and identified as a barrier of cancer treatment during Covid 19 Pandemic.

The issue of transportation was also addressed as barrier in other studies also (Lin C C, 2015). In this study, post-operative patients of colon cancer assessed for travel distance, density of oncologist and acceptance of chemotherapy. Results showed that travel distance is a factor for receiving chemotherapy and those who needed to travel 50-249 miles had less chance of getting chemotherapy than those traveled less than 12.5 miles. It is clear that traveling distance has the potential capacity to influence negatively to receive cancer care. This is similar to the problems of increased travel expenses and insufficiency of vehicle which occurred during Covid 19 Pandemic. Such problems dictate to develop peripheral health institutions for rendering cancer care so that necessity for travel for the cancer patients may be minimized.

To understand the priorities of the patients and their caregivers, during the interview a set of closed ended questionnaire used with an open ended question “any other point”. Various topics those were included are like problems related disease, doctor’s appointment related problems, to seek counseling for the disease status, searching of a particular health care related problems along with one open ended option to mention further problems beyond the structured questionnaire. Below mentioned table carries the results.

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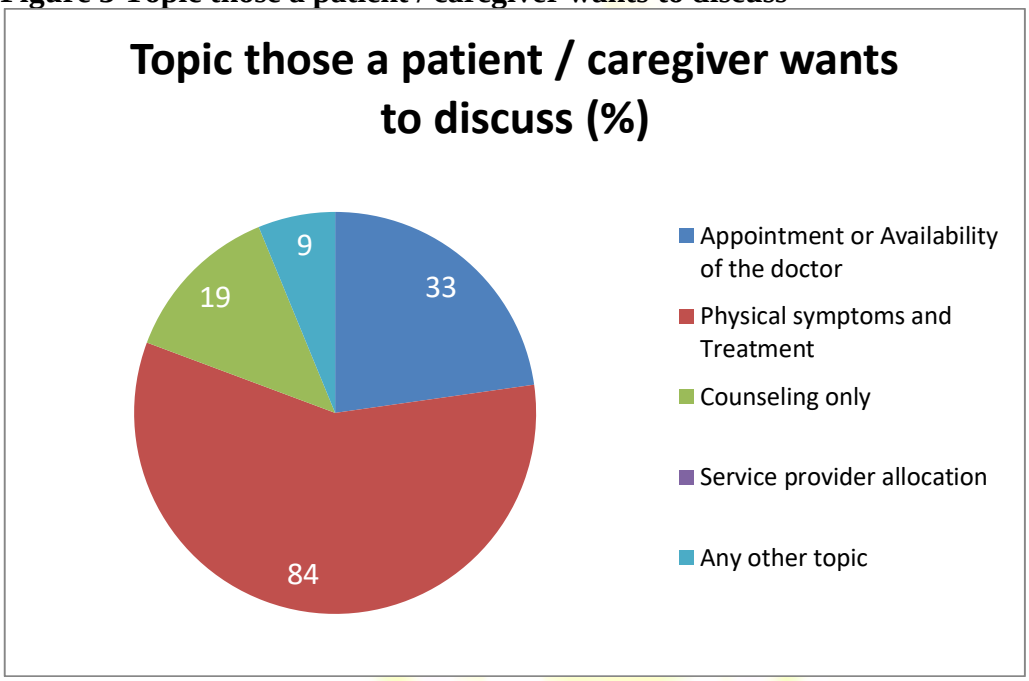
Table 3 Topic those a patient / caregiver wants to discuss %

Topic those a patient / caregiver wants to discuss (results are in percentage)		
1.	Appointment or Availability of the doctor	33
2.	Physical symptoms and Treatment	84
3.	Counseling only	19
4.	Service provider allocation	0
5.	Any other topic	9

Figure 3 Topic those a patient / caregiver wants to discuss



Results show that most of the patients or care givers during this Covid 19 Pandemic period wanted to discuss about various physical problems faced by the patients due to illness. The figure is as high as 84%. Availability of the doctor or appointment of the doctor is of concern for 33% patients and their caregivers and to get counseling is concern of 19%. A small fraction of sample (9%) wanted to discuss some other issues. Here, one important point was that none of the sample population wanted to know about a particular health care provider; rather they wanted to depend on the system and expressed no concern about any individual health staffs including doctor.

In the website of ASCO about Palliative Cancer Care (ASCO, 2019) it is mentioned that there are several topics which need to be addressed in palliative care. Both the disease cancer and various treatment modalities of cancer are capable of producing physical problems and also treatment related side effects. There may also be associated financial, psychological even social difficulties. In present day norm, from the first day of diagnosis all these issues are taken in to consideration. A patient with good palliative care should show good quality of life during the journey of cancer. Hence, assessing the issues which are important from the point of patient and care givers of the patients is very important, relevant and significant.

In the present study, it is found that most of the patients and their care givers wanted to discus regarding various physical symptoms. Symptoms of a cancer patient were also assessed by other articles like (Henson L A, 2020) where 11-point number rating measurement was used to calculate

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the frequency of nine complains. These included symptoms like pain, vomiting tendency, gloominess, fatigue, worry, hunger, lethargy, breathing difficulties and overall general feeling. So, it can be commented that physical symptoms are significant for a cancer patient on follow up.

In the present study, it is found that concern about physical symptoms was a priority to most (84%) of the participants. During Covid 19 pandemic whether doctors will give appointments or whether doctors are available was important to about one third people (33%) and around 19% of the sample population was also wanted to get counseling. So, implementation of these findings will show that physical symptoms are still very distressing to the patients and they want to get rid of these. Availability of Doctors and availability of care givers were important to many people because truly many health care facilities were overwhelmed due to Covid 19.

At this point, it is worthwhile to mention about Operational Guidelines of National Program for Palliative Care (NPPC), Government of India (DGHS, 2017). NPPC was constituted in 12th Five Year Plan and declared as a part of National Health Mission (NHM). This program was aimed to improve availability and accessibility of palliative care to the people who need it. It also provided good pain relief. The program was made a part of Health Care at every stage and deployed to work as per the requirement of the community and to cover cancer and other Non-communicable diseases. The packages of services start from Health Wellness Centers up to Tertiary Care Facilities and providing good palliative care in District Hospitals, Community Health Centers. Home based palliative care for the bedridden patients also incorporated in the package. NPPC is a complete, comprehensive and planned program which is capable of providing care, practically at all levels. Such services are capable to meet the need of well-organized care during Covid 19 Pandemic also.

Conclusion

To reduce the traveling requirements of cancer patients, follow-up clinics at peripheral health institutions (like district and sub-divisional levels) may be encouraged and basic supportive medications and counseling may be provided there by trained professionals. As physical problems and treatment-related discussion are vital issues for the patients and their care givers, necessary communication can be done either by home care or by caring at nearby health institutions. Side by side, mobile phones can be used for communication, and both audio and video calls can be made as per convenience and necessity.

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Annexure

Tables:

Table 1: Possession/Accessibility of Android/ Touch Phone/Phone with Audio-Video capacity
Table 2: Problems during COVID10 Period in percent (%)
Table 3: Topic those a Patient/ Caregiver wants to Discuss (%)

***Figures*:**

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