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To what Extent is Financial Toxicity an Unrecognized Oncology Symptom and How Frequently is it Characterized by Insufficient Patient-Advocacy?

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Abstract

Purpose/Aim: The purpose of this study was to investigate the breakdown in communication between Medical Schemes, patients and Health Care Providers (oncologists) with regards to benefits, limits, copayments and exclusions, leading to Out of Protocol requests and unrealistic treatment expectations on the oncology patient's behalf, ultimately leading to patient's financial toxicity.

Design and Methods: Quantitative methods were used to obtain data from E-Auth for cost comparison for chemotherapy drugs, surveys were sent to case managers of various schemes as well as oncologists.

Results: 100% of doctors had heard the term financial toxicity, while only 50% of case managers had heard the term.

90% of the doctors spoken to said they took the patients benefits into consideration. 80% cautioned against the expensive treatment.

100% of doctors stated they knew what PMBs were, while 95% of Case managers stated they knew what PMBs were.

90% of doctors communicated with the schemes, 70% of case managers discussed consequences with patients.

Conclusion: Both doctors and Case managers feel as though they communicate sufficiently, even though data shows that 40% of patients in the USA file for bankruptcy within the second year of a cancer diagnosis. Financial toxicity is one of the top side effects of chemotherapy, next to nausea and vomiting. This is due to Medical Schemes using Utilisation Management in place of correct and qualified Oncology Case Management creating a barrier to successfully advocating for the patient.

Definitions

Case Manager: According to the Case Managers Association of SA and Case Managers Associations worldwide, the accepted definition of Case management is the collaborative process of assessment, planning, facilitation, care coordination, evaluation, and patient advocacy for options and services to meet the patients and family's comprehensive health needs though communication and the use of available resources to promote patient safety, quality of care and cost effective outcomes.

Utilization Management: Utilization management is the cost containment of managed care using three types of review of behalf of medical schemes to manage health care costs by reviewing the medical necessity appropriateness and reasonableness of requested treatment for patients. This can be Prospective Review (Pre-Auth), Concurrent Review (Updates of Auth) or Retrospective Review (Review of Auth done post Discharge or on Account received) and is done on a case by case basis.

Co-Payment: This differs from scheme to scheme; it can be a percentage or rand value as fixed amount of what the patient is liable for. This co-payment cannot be paid from the patient's savings. As per the council of medical schemes a co-payment cannot apply to PMB's or PMB level of care as long as scheme rules and designated service providers are followed and used. If a patient does decide not to follow the rules and use a Non-DSP or Off Formulary medication, even if the treatment and the condition is PMB, the patient is liable for the co-payment- this can be either a percentage or difference in cost.

Designated Service Provider: Patients are restricted to using DSPs- a specific network of specialists. Use of outside service providers may result in a co-payment, unless it is an emergency or there are other technical reasons.

Financial toxicity: The financial burden resulting from cancer treatment is referred to as financial toxicity. Oncology patients experience greater out-of-pocket costs, loss of income and care giver burden than most other medical patients or the general public.

Prescribed Minimum Benefits: These are a set of defined benefits as set out by the Counsel of Medical Schemes, of 270 conditions that a scheme must cover in full regardless of a patient benefit, or limit. PMB level of care is defined as the same care or treatment a State patient would receive for the same

condition. This means a patient can have a PMB condition but not receive PMB treatment, or be receiving PMB treatment but the patient's condition is not PMB.

Restricted Medical Scheme: These are Schemes that are linked to companies and only employees and their families of these companies may join. There is normally no general or condition specific waiting period applied to these members but there are Late Joiners Penalty fees that can be imposed for older members.

Open Medical Scheme: These schemes are open to all members of the public. They cannot refuse any application based on age or health status; however, they can impose General, or Condition Specific waiting periods depending on the number of previous years on a scheme. The scheme can also apply a Late Joiners Fee for older members who have a broken or no medical scheme history.

Quantitative Method: Quantitative Research is used to quantify information by way of generating data that can be transformed into usable statistics. These statistics are used to quantify attitudes, opinions, behaviours, and other specified variables from a sample population. It uses measurable data to formulate facts and uncover patterns in research. The collection methods are much more structured than Qualitative data. Qualitative methods might be used to understand the meaning of the conclusions produced by Quantitative methods.

Using quantitative methods, it is possible to give precise and testable results to qualitative ideas. A combination of quantitative and qualitative data gathering is often referred to as mixed-method research.

Abbreviations used:

CM	Case Manager
UM	Utilisation Manager
DSP	Designated Service Provider
NON-DSP	Non-Designated Service Provider
PMB	Prescribed Minimum Benefits
CMS	Council of Medical Schemes
MEM	Member

Introduction

Rising costs of Oncology drugs and treatment in South Africa have left patients faced with a new symptom that is often ignored. That of Financial Toxicity. Financial Toxicity directly results in significant out of pocket costs to the patient, loss of income due to extended sick days during chemo, radiation and surgery, and the burden of the family caregiver. This often leads to lack of compliance in treatment and decreases the patient's chances of survival.

The total cost of cancer care in 2009 in the USA was more than $133 billion (this included healthcare costs; loss of productivity and loss of family savings). In 2020 in the USA the same cost is expected to be $173 billion. With the advancements in medicine and science, the population of 65 years and older will represent over 20% of our population *vs* only 12% in 2012. This will lead to huge cost burden increase burden to Medical Scheme schemes, patients and families, as 67.20% of the cancer population is between 50 years and 70+ years. This same age group only represented 60.94% of the population in 2009, showing a 6.7% increase in survival. This is where the financial toxicity starts to show. This same population is also the population that least understands today's technology and Medical Scheme Rules and Jargon leading to a combination of confusion and a desperate need to stay alive. The misinformation that they are often given by providers, uneducated Case Managers and scheme staff and brokers, leads them to believe they are fully covered, their condition is PMB and must be paid in full or its their right to use whomever they choose. When they are told there may be a co-payment, no-one takes the time to explain the exact implication of that co-payment, and by the time authorisation is granted and treatment is started it is too late. The patients are often told they have a 20% co-payment which can seem insignificant but as shown by the table below 20% can range from R20 000 to R100 000 per month and is often required up front.

Action	Cancer	Est Cost per month	Facility Fees	Total	Med Aid 1 Co Pay*	Med Aid 2 Co Pay#
CTLA-4 Blocking Antibody	Melanoma	R 245,000.00	R 4,800.00	R 249,800.00	R 100,000.00	R 50,000.00
PD-1 Blocking Antibody	Lymphoma	R 190,000.00	R 8,700.00	R 198,700.00	R 80,000.00	R 40,000.00
EGFR Antagonist	Head and Neck	R 129,000.00	R 33,200.00	R 162,200.00	R 65,000.00	R 30,000.00
BRAF V600E Inhibitor	Melanoma	R 100,000.00	R 1,000.00	R 101,000.00	R 40,000.00	R 20,000.00
PD-1 Blocking Antibody	Melanoma	R 95,000.00	R 4,800.00	R 99,800.00	R 30,000.00	R 17,000.00
CD30 Antibody	Lymphoma	R 65,000.00	R 4,800.00	R 69,800.00	R 28,000.00	R 14,000.00

Microtubular Inhibitor	Hepatic	R 65,000.00	R 14,200.00	R 79,200.00	R 30,000.00	R 15,000.00
CD20 Mytolytic antibody	Lymphoma	R 62,000.00	R 4,800.00	R 66,800.00	R 27,000.00	R 13,000.00
Thalidimide Analogue	Lymphoma	R 60,000.00	R 1,000.00	R 61,000.00	R 24,000.00	R 12,000.00
Kinase Inhibitor VEGF Antagonist	Colo-Rectal Cancer	R 50,000.00	R 1,000.00	R 51,000.00	R 20,000.00	R 10,000.00
	* Based on Med aid with 40% co pay per cycle# Based on Med aid with 20% co pay per cycle					
	# Based on Med aid with 20% co pay per cycle					

Table 1: Comparison of Co-Payments.

PATIENTS above were all loaded using electronic authorisation system, higher medical scheme facility fees, with a height of 1.75 m, weight of 80kg and a bsa of 1.97 based on 1 cycle of each drug.

Note: Costs have been rounded down to the nearest R100 for legal reasons only the action of the drug has been specified.

The above table compares some of South Africa's most expensive drugs. These biological drugs are least likely to be paid for by Medical Schemes due to high cost.

I looked at the facility fees that would be charged, one cycle of each drug and the total cost. I then took two (2) different well known, Open Schemes in South Africa and applied their co-payment rules.

If the Scheme declined to pay for the treatment but the patient decided to go ahead anyway the TOTAL column would be the amount that the patient or their family would be liable for, per treatment cycle. If the Scheme approved treatment within the benefit available but applied a 20% co-payment, the member would be liable for the amount in the second column, until all benefits were depleted and then they would be liable for the full amount.

If the Scheme approved the treatment within the benefit but applied a 40% co-payment, the member would be liable for the amount in the third column until benefits were depleted and then they would become liable for the full amount.

This could leave families who are already struggling to make ends meet, bankrupt- many resorting to second bonds or putting their houses on the market as well as taking out loans to pay for the copayments for treatments they have been told are best for them without any full and proper explanation of the financial consequences.

Many are given the option to upgrade their Scheme benefit from a lower option to either the higher or highest option. This too has Financial consequences as shown below. As Case Managers and Oncologists, we provide the patient with expensive treatment that requires upgrading. When the patient upgrades to receive this treatment, they are now looking at an increased monthly cost for Medical Scheme contributions. On top of this, once the benefit is depleted the patient remains liable for the continuation of his treatment until his new benefits begin. This often results in one of two scenarios:

1) The patient pays the increased benefit and the continuation of care due to depleted benefits, he has to get financial assistance, either in the form of loans or selling assets.

2) The patient continues paying the increased benefit and becomes non- compliant in treatment while he waits for his new benefits to start. During this time, he hopes he doesn't progress. This starts a cycle of on again, off again treatment while the patient has benefits, until he progresses. This could become very costly for the scheme as the patient moves to palliative stages.

Patients don't always understand that, while they will have increased benefits, these benefits are prorated to start with, so the amount that they are expecting is not the amount that they will have access to. Case Managers often neglect to explain this to emotional patients when upgrades are suggested (Table 2).

Medical aids				**Main Mem cost**
Medical Aid A	Low Option	PMB Benefits	Closed Scheme	R 1,185.00
Medical Aid A	Top Option	Biological Benefits	Closed Scheme	R 2,500.00
Medical Aid B	Low Option	PMB Benefits	Open Scheme	R 1,488.00
Medical Aid B	Medium op	PMB Benefits	Open Scheme	R 3,234.00
Medical Aid B	Top Option	Biological Benefits	Open Scheme	R 8,202.00
Medical Aid C	Low Option	PMB Benefits	Open Scheme	R 1,731.00
Medical Aid C	Medium op	PMB Benefits	Open Scheme	R 3,581.00
Medical Aid C	Top Option	Biological Benefits	Open Scheme	R 6,438.00

Table 2: Comparison of Medical Scheme Benefit Costs.

In a US study, of 1202 adults suffering from cancer, 20.4% reported they had financial difficulties directly related to their illness and could not pay their cancer related medical bills, having to borrow money, sell assets, go into debt or file for bankruptcy. 174 of these patients reported "significant or catastrophic" financial burden. Sadly, it is often the younger or poorer families that bear the financial brunt because they have little to no savings built up to fall back on and sometimes little or no assets to sell or use as collateral for loans. Leaving them with little to no financial security to help finance expensive treatments.

These above-mentioned costs don't even cover the shortfalls on NON PMB accounts; co-payments due to inaccurate information on benefits and other costs associated with the chemo treatment itself.

The diagram below shows how Financial Toxicity results from the both Objective Financial Burden and Subjective Financial distress that the patient experiences while on cancer treatment. This financial hardship is internationally recognising both the material consequences as well as the emotional and physiological impact of both the treatment and the cost. As the patients become more distressed about the cost of treatment and other financial obligations their ability to cope decreases, this can then present as worsening symptoms and adversely affect the patient's overall outcomes (Figure 1).

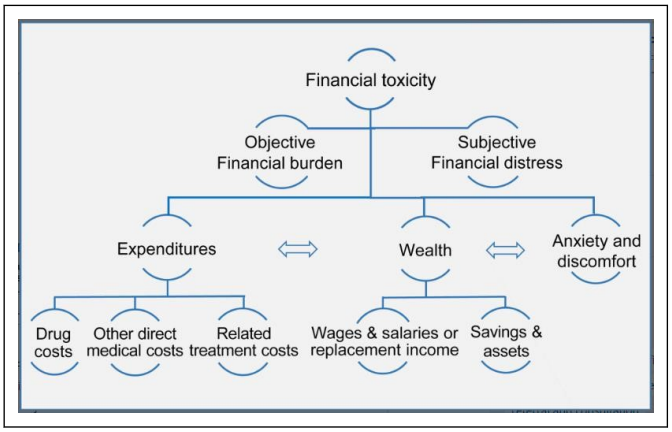

Figure 1: Conceptual framework of financial toxicity in oncology patient.

Patients with cancer, who have no Case Manager to guide them through the obstacles of how Medical Schemes work and where their treatments are authorized from and which benefits their required resources should pay from end up with an accumulation of accounts that are often short paid or paid from the wrong benefit or patients are given incorrect advise to upgrade. These all exacerbate an already financially constrained patient and family.

This leads to patients downscaling their standard of living to ensure their loved one gets the treatment they need and when the scheme declines treatment due to no funds, this often leads to non-adherence on the part of the patient as they can't afford the treatment that is needed.

This then results in disease progression, having devastating clinical and socio-economic consequences on both the patient and the family.

Financial Toxicity is not seen as a side effect equivalent to nausea and alopecia but their effects on the patient as just as overwhelming. Although the chemotherapy drugs are vital to the progression free survival of the patient, the use of these drugs subject the patient to extreme financial hardship. Unfortunately, the full impact of Financial toxicity on oncology patients is not fully understood, although it has been vigorously studied for many years. One thing we are sure of, is that it is not only a patient's savings that is affected due to costs that out-weigh what the scheme pays, but also the cost of the burden on Caregivers, cost of transport to and from treatment, financial impact due to lost work productivity and running out of sick leave days and this also directly affects the company, as they must employ temps and pay sick leave for the employee (Figure 2).

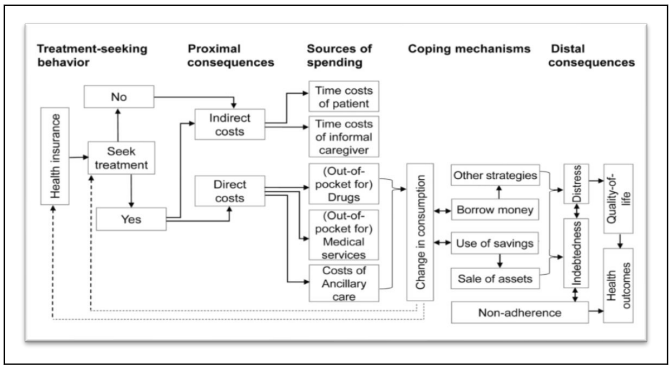

Figure 2: Economic consequences of cancer treatment on a patient.

Case Managers in the Oncology Practices and Managed Healthcare Organisations can work together to help patients understand what their benefits, limits and costs will be before they become a burden. Patient Centered Care does not just revolve around quality of care but also to help contain the financial burden that can follow. For decades it's been assumed that oncologists had no legal obligation to discuss financial implications of treatments with their patients. However, with the steep cost increases and the dramatic increase in the number of cancer diagnoses year on year, evidence shows, most oncology patients deem financial information crucial. One study showed the59-80% of patients wanted their Oncologists to discuss their healthcare costs with them when obtaining patient consent or discussing treatment plans and pathways.

High-quality, peer-reviewed Clinical Pathways and protocols provide a suitable Utilization Management Tool for Managed Healthcare Organisations thus ensuring cost-effecting cancer treatment while safe-guarding patients benefits, especially on the lower option schemes.

These evidence- based pathways ensure schemes and oncologists provide the patients with the best care available within the benefit structure the member has chosen. However there needs to be a strong separation between Case Manager and Utilisation Manager and more communication between

Oncologist and Case Manager while keeping the whole system ethical and Patient Centric.

This was made no more obvious than a study done by JC Spencer et al There were Seventy-eight (78) participants in the survey who commented on their experience with Financial Toxicity in one form or another by answering several Financial and treatment related questions. Only 45% felt that there was some financial assistance available. 50% felt that the barriers included lack of resources. 46% felt that the patient's barriers were due to a lack of knowledge about their scheme and benefits. 20% felt that the complex and duplicative paperwork for patients was a barrier.

Methodology

Oncology Case Managers and Oncologists from around South Africa were identified as Survey subjects based on response to request emails sent to Oncology Departments and Practices, requesting participation.

Research questions were drawn up using framing research questions based on PICO (T) quantitative surveys (figure 3).

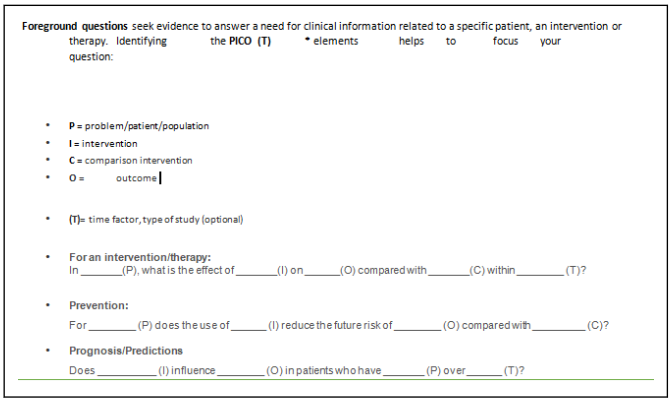

Figure 3: Using pico (T) to formulate clinical questions.

These questions were then set up on two (2) different Survey wizards- Survey Monkey for the oncologists and SurveyPlanet for the Case Managers. The only reason for this choice was SurveyPlanet allowed 25 free questions and Survey Monkey allowed 10 free questions. From experience doctors participate more willingly in questionnaires with many questions.

Refer to Annexure C: Ethics Approval and Email requests for assistance to both Oncologists and Case managers All the questions were multiple choice and had no need for long explanation, thus keeping the survey as short and comprehensive as possible. It also helped maintain objectivity rather than subjectivity on many questions. It was also set up so that every person who took the survey could be anonymous.

All subjects were given two months and a follow-up email before the surveys were closed off online, to prevent late participation. All data was collated and can be found as Annexure A and B.

Using Quantitative Data provided by Business Data and Test Patients loaded on Electronic Authorisation System, using the same patient information below (175cm was the chosen average height as the accepted average male height in the world) (Figure 4).

Height (cm)	Weight (kg)	BMI	BSA
175.00	80.00	26.12	1.97

Figure 4: Patient infographics used for generic patient for pricing on drugs shown in table

This gave me a cost analysis of the 10 most expensive oncology drugs by drug and disease currently being requested within the Oncology Framework.

I then took two (2) similar benefit schemes that have co-payments that are applied for the same reasons, and worked out the co-payment a patient would have in each case based on 3 scenarios.

1) The Medical Scheme declines authorisation and the patient becomes liable for treatment.

2) The Medical Scheme approves treatment within the benefit and applies the copayment of 20% .

3) The Medical Scheme approved treatment within the benefit and applies the copayment of 40%.

It is important to note that in both scenarios 2 and 3, once the patient runs out of benefits, they will be liable for the full cost of the treatment as well as Medical Scheme premiums as well until the new benefit cycle commences.

Using each Medical Scheme website, three (3) Medical Schemes were chosen and their bottom plan, mid-level (if there was one to select) and top (with access to Specialised drugs) were selected. One (1) was a Closed Scheme and two (2) were Open Schemes. I then looked at the cost for the Main member's premium only and then compared the difference in cost if the patient were forced to upgrade due to benefit constraints. This then gives an idea of additional cost burden placed on a patient by Oncologists and Case Managers by, what is a helpful but expensive solution.

Survey Questions

Surveys were sent out to the two of the main role players in the patients' journey- The Oncologist and the oncology case manager. Thirty-six (36) Case Managers agreed to participate in the survey and received the email request for the survey. After two (2) months of reminder emails and follow-ups I received twenty (20) responses of which one (1) was not usable.

Formal Training

When asked how many had received formal training in Oncology Case Management only 25% had while 60% had not. 15% of the respondents' preferred not to answer.

Understanding of Terms used

The Oncology Case Managers were asked if they had heard of the term Financial Toxicity and only 50% of the respondents' said yes.

The Oncology Case Managers were asked if they understood how PMBs worked as per the CMS guidelines with regards to oncology and if they could explain these rules to their members in a clear and concise way. 55% said they definitely could while 40% said they felt comfortable doing so.

Oncology Treatment Plans

The Oncology Case Managers were asked if they contacted the patients to inform them of the financial consequences of the doctor's treatment choices. It is concerning that 10% said they were unsure or did not contact the patients at all. However, 85% of the Case Managers responded that they did.

Benefits and Guidelines

The Case Managers were asked if, when they contacted the patients, they explained the co-payments, sub-limits and other rules and benefits. They were also asked if they contacted the Oncology Practices with this information. 90% surveyed stated that they did.

Case Managers were asked if they felt competent to empower, guide and support members and family through the complex process of Oncology Pre Auth and as well as during and after treatment to ensure benefits were correctly utilized. 85% felt that they were able to do so while 15% stated the were either unsure or were unable to assist.

Case Management and Patient Advocating

Case Managers were asked if they advocate strongly for their patients, negotiating with the schemes and Doctors to assist the patient with their financial and treatment needs that are in the best interests of both the patient and the Scheme. It was interesting to note that 20% of the Case Managers were unsure of this, where this is considered a core function of a Case Manager. 80% said they do advocate for their patient.

Case managers were asked if they felt they were given sufficient time to assist patients as proper case managers and a staggering 65% felt that they had insufficient time to do so.

The next Role Player surveyed were the oncologists fifteen emails were sent out to Practice Managers requesting assistance from their oncologists. Of these ten oncologists replied.

Refer to Annexure B: Oncologists Survey

80% of the surveyed oncologists had been in private practice for more than ten (10) years.

Understanding of Terms

All Oncologists surveyed were asked if they had heard of and understood the term Financial Toxicity and they all had.

When the Oncologists were asked if both, they and their staff understood PMBs as per the CMS guidelines and regulations 70% said they did and 30% said they definitely did.

Benefits and Guidelines

The Oncologists were asked specifically about how they understood the various scheme benefits and communicated these with the patients they saw. 90% of the Oncologists stated they did understand the scheme benefits and they did communicate these with the patient.

When the Oncologists were asked if they understood why there are limits and DSPs especially when linked to high cost drugs 40% said No while 60% said Yes.

Treatment Decisions

The Oncologists were asked if their treatment decisions were ever based on patient benefits and if the patient's financial status was ever taken into account. 90% said that they did take the benefits and financial status of the patient into account when choosing treatment. 70% said they discussed the patient's treatment choices and cost implications with the patient, 10% said they didn't and 20% said they didn't know or were unsure.

Scheme Collaboration

When asked if either they or their staff interacted with scheme Case Managers to ensure patients did not incur unnecessary costs 90% said they did

Patient Advocacy

The Oncologists were asked if they caution patients about making emotional decisions with regards to expensive and non-Protocolised treatment and that their decision could have short-term and longterm financial implications on themselves and their family- 80% said they would and do, while 20% said they wouldn't and don't.

Results and Findings

When receiving the information back from the Case Managers and the Oncologists there were several obstacles and biases that affected these findings. Some are not of great importance however one or two did impact some of the findings.

The first bias is that all the Case Managers that were contacted and responded were female. This is due to there being few if any male Oncology Case Managers within the Managed HealthCare system. The bias this creates is females may respond to surveys differently than males might, thus giving the survey a slightly biased slant.

The second bias that was encountered was the fact that two (2) Case Managers who participated in the survey asked that their results not be used in the survey- this is obviously not possible as it was an anonymous survey and I could not separate the different answers. I had to work on the assumption that if a person decided to complete the survey but as a non-

participation, then at least 2 of the "non- specific" answers for each reply belonged to these 2 participants.

Case Manager Feedback:

Formal Training

Training seems to be a problem that needs to be addressed. As noted in the comments made by some Case Managers (last part of Annexure A). It has also been noted in several instances that Managed Health Care companies and Medical Schemes do not allow Oncology Case Managers to take their education into their own hands but prefer to deal with training in house. Any Oncology related seminars or talks need to go via management, and they decide who goes to them. This causes a vacuum in education and employee development as well as an information breakdown- meaning some Case Managers get educated externally while others must wait for this information to be fed down to them and this doesn't often happen. There are many websites available for On-Line training. There is now also a Case Managers Certificate course available in South Africa as well as free Oncology training.

Oncology is not the only form of training required- Understanding the correct use of ICD10 codes as well as the knowledge of the correct use of PMB rules is also a vital skill. A skill that few Case Managers have- relying on incorrect histology reports and ICD10 codes. This leads to incorrect auth coding and claims payments- ultimately leading to the member being responsible for accounts they should not be.

Many Case Managers, unfortunately, do not realise that all the training they need is available to them- much of it for free. In my experience in dealing with the various Case Managers, education on the above levels is where the system starts to fail the patient, and where we can start to repair it in order to protect patients from the financial distresses they often endure.

Understanding of Terms used

It was a surprising result that so many Case Managers say they know and fully understand the terms regarding PMB. The reason this is so surprising is due to the number of patients who call asking for information about PMB with regards to Oncology and have been given incorrect information by Case Managers and admin staff or Treatment plans that have been authorized incorrectly, based on scheme rules and benefits rather than correct PMB rules.

From this we can assume that, while many Case Managers think they understand PMB rules, in reality, they understand the scheme rules and not PMB or CMS regulations. This leads to Financially toxic treatment denials or authorisations being made that are due to erroneous and incorrect information being given to the patient.

Oncology Treatment Plans

When loading treatment plans many Case Managers apply the PMB rules incorrectly as well as copayments that are not discussed with patients.

Many Case Managers work on a Utilisation Manager system of loading what fits within the benefit and not checking what has been previously sent in by Oncology practices. This often leads to plan overlap or duplication.

Some also do not understand the DSP rules and agreements their schemes have signed. While this is also a training issue, it becomes problematic when incorrect codes are loaded, and these deplete the oncology benefit. A Case Manager should know the rules and be able to apply them in such a way that they can approve and decline facility codes based on the knowledge of the DSP rules and regimes, without unnecessarily depleting the patients benefits.

Benefits and Guidelines

It is very concerning that so many (15% of the Case Managers surveyed) felt that they would be unable to assist a patient navigate the Oncology Medical Scheme world. As a Case Manager, their main functions are to advocate, facilitate and navigate the Oncology system with the patient and ensure their authorisations are correctly loaded, with benefits correctly utilised. If this is not occurring, then members are not receiving the assistance they require from their Case Managers. This leads to lack of knowledge about benefits and limits on the members side. Incorrect payment of accounts by the claims department and then the patient being incorrectly liable for accounts that should be paid from either Oncology benefits or PMB. Again, this leads back to a training issue that can easily be resolved so that the patients can benefit from qualified Oncology Case Managers not Utilisation Managers loading plans.

Case Management and Patient Advocating

It has become clear from patients and from responses, that the Case Managers are no longer fulfilling the correct roll of Case Manager but rather a role of Utilisation Manager. This is concerning as it is detrimental to the patient and their financial and social wellbeing, as there is no support structure, only authorisations. We need to balance the departments to ensure that, while there are UMs there are CMs as well who can assist the patients every step of the way, providing correct information, ensuring correct benefits are used and correct Resource Management occurs. Patients will benefit from this support both financially and medically, leading to better adherence and outcomes.

Oncologist Feedback

Understanding of Terms

This feedback is similar to that of the Case Managers- While oncologists believe they do know what is PMB and what is not, many confuse PMB LOC and PMB conditions and this often leads to unnecessary conflict with schemes for denied auths. Many also do not understand the rules on how PMBs are covered and paid and this causes financial backlash on patients. Many doctors don't understand the importance of correct ICD10 coding and this, again, leads to incorrect authorisations loaded and accounts not being paid correctly based on DSP rules.

Benefits and Guidelines

As an oncology Case Manager at a DSP I often notice from the requests submitted and the queries received that many

oncologists either rely on staff to provide the benefit details or for the patient to know what they have access to. Many times, the treating oncologists are not even aware of how much the treatment is that they are requesting.

It also raises concern that 40% of the surveyed Oncologists did not understand the reasons behind schemes having DSPs, co-payments and limits especially of High cost drugs and Specialised Drug benefits. Oncologists often feel that being channelled by a Protocol and by benefits and limits, that their ability to treat their patients to within their best medical ability are compromised. However it is often acknowledged in the same breath that the cost of oncology is not sustainable within the South African setting and that many schemes are likely end up bankrupt should many of their patients have the drugs mentioned in the above table approved, while paying the current benefit premiums.

Treatment Decisions

It is definitely shown to be true that oncologists try to look out for their patients when looking at the data collected within the Managed Healthcare In-Protocol data collected. However, some doctors who were polled felt they were there to treat the patient and not worry about the financial implications. As a Case Manager I see this daily in the 14% of Out of Protocol plans that are reviewed by the DSP review committee where Oncologists sometimes request R600 000 treatment for patients on PMB scheme options.

Scheme Collaboration

There is a breakdown in communication between the Doctors providing the treatment, the Case Managers in the Practice and the Case Managers who are authorizing the treatment. The case managers in the practice load the plans with as many conceivable items that they may need, forgetting that all these items add up and accumulate towards the total of the patients oncology benefit. the oncology benefit becomes a target to reach rather than the patients financial well-being being something to consider. The scheme case managers work on what is seen as an authorised total not a paid total and for this reason will stop authorizing once the limit has been reached. So if a doctor has requested a treatment and then another without communicating the reason for the change, the auth is not updated in full and the patient is then seen as having used up benefits that were not in fact used. This puts financial strain on the patient when auths are incorrectly denied- leaving the patient liable to pay for treatment.

Patient Advocacy

As Case Managers, we need to notify the practice when there is a co-payment due for treatment we have also found that while many of the Oncologists are aware of the co-payments the patients may have to pay for Out of protocol treatment or for Specialised Drugs, as demonstrated in Table 1: Comparison of Co-Payments, some of the practices prefer to submit plans that could incur these financially toxic situations for the patient prior to discussing the implications with the patient or even being sure if the financial impact is one the patient can absorb. They only explain the implications once the treatment is approved by the scheme.

This, in essences, goes against the Patient Charter which states the Patient has the Right to make an informed decision; the patient has a Right to knowledge of their medical scheme and the participation is decision making. However, many practices would rather see if the treatment will be approved before discussing it further with the patient.

It should also be noted that in the survey some Oncologists did not feel that the financial implications or welfare of the patient was their responsibility- Their responsibility was to treat the patient to the best of their ability. This leaves the patient open to being non-compliant and could possibly lead to disease progression due to on-again-off-again treatment while there are benefits available.

Discussion

How should Oncology Case Management be done to prevent Financial Toxicity

There are three (3) different types of assistance the patient encounters within the realms of “Care Management”. These are Patient Navigators, Utilisation Managers and Case Managers.

Many practices have implemented Patient navigators- These staff members’ functions are to provide assistance with navigation through the complex health care system- this includes getting appointments with all the specialists on the same day to reduce transport difficulties and costs. Assist with circumnavigating the hospital, scheme and human bureaucracies by providing information and support. They need to assess the patient’s current needs, identify the barriers to care, and assist the patient by providing resources and information to eliminate these barriers.

Patient Navigators’ Roles form part of what a Case Manager does and, when there is a Patient Navigator available, a Case Manager should use Patient Navigators as an additional resource.

Patients encounter Utilisation Managers on Scheme level rather than Case Managers. A Utilisation Manager’s sole task is to evaluate the appropriateness and efficiency of the health care services being requested, according to the protocols and guidelines within the benefits and limits of the patients plan. The UM is not there to assist the patient but rather to ensure the scheme’s money is well spent.

These terms and responsibilities are often confused but it should be noted that while Utilisation Management and Patient Navigation both have independent roles, Case Management is an allencompassing field requiring knowledge of Patient Navigation, Utilisation Management as well as well as other collaborative and negotiation skills.

When UMs’ are solely responsible for the management of an Oncology Patient then the advocacy of the patient falls by the wayside as was shown in a patient case-study (Module 4 final case study Case Management).

Patient X is a 44-year-old female who, after finding a large lump on the outer part of her right breast, was referred to a wellknown breast surgeon for a biopsy. Unfortunately, no one at the scheme nor the doctor explained that she was at non-DSP.

Patient X was also a new member on her Medical Scheme, due to this, her request for authorisations were sent for investigation with regards to non-declaration of oncology history.

The patient was referred by the Breast surgeon to Oncologist A. Further frustration awaited her. She wasn't informed of the DSP rules within her Medical Scheme and she had been referred to an oncologist that would impose a non-DSP co-payment for all her treatment. I contacted her after her fist consult and initiated case management and this is when her Medical Scheme benefits were explained to her.

I took over as Primary Case Manager and worked with the UM team at the scheme- by doing this it ensured that I could advocate for her through all stages of her care, between all specialists, hospitals and the scheme involved. I assisted in moving her from a NON DSP (oncologist A) to a DSP (oncologist B) I ensured all copayments that were imposed were correct and all accounts were paid correctly (Table 3).

PT	Oncologist A	Oncologist B
Systemic Chemotherapy	R429,940.41	R 399,032.09
Consult	R 19,643.70	R 0.00
Facility	R 180,106.00	R 110,365.00
Radiation Professional fee	R 29,491.46	R 23,620.00
Radiation Technical fee	R 90,749.83	R 91,438.00
Total	R 749,931.40	R 624,455.02
NON-DSP* Co-pay	R 74,993.14	R 0.00

Table 3: The resulting saving for the patient due to co pays she would have had to pay on top of her needing to upgrade her plan, shortfalls on other non PMB costs.

This R74 000 was an amount that she was not told about, by the scheme UM or by the NON-DSP Oncologist when they discussed the treatment. No-one helped her navigate the specialised and highly fragmented Medical Scheme system we have. This unnecessary additional cost would have added to her financial toxicity and oncology related stress.

Case Managers should have considered the implications. The practice Case Manager should have notified this patient of the co-payments she was likely to incur and why, and how this could be solved. The Scheme Case Managers should have stopped being Utilisation Managers only and helped the patient navigate the different parts of this process. Helped ensure the non-declaration was completed quickly, explained DSP and NON-DSP rules as well as the cost to the patient could incur. Each time she asked for help or an explanation, there should have been someone to guide her through the process and not allow her to flounder.

Case Managers should have the expertise, knowledge and compassion to be able to manage a patient's oncology treatment plan by ensuring that quality of treatment AND cost control is maintained while advocating for the patient's interests. It is important to look at providing correct patient education and promote patient self-advocacy by ensuring patients are empowered with knowledge of their benefits, limits, DSPs' as well as the PMB regulations and rules.

Scheme cost savings do not rely on inaccurate claim payments and plan denials but rather on timely authorisations, alternative treatment options when what is requested is not within benefit, correct DSP network steerage and most important, ensuring the correct and appropriate use of Protocols by Oncologists and treatment reviews where needed.

It also relies on open communication between patient, provider and managed care organization.

There are five domains where Case Managers can make a difference: empowerment, adherence and compliance, coordination of care, knowledge, and safety.

Empowerment is the portal to all the other four domains. Patients may not be able to control the cancer, but they can control when and where they receive treatment, when to make the decision about palliative care, and who to see for a second opinion. Case Managers want to help patients to feel educated and informed.

Case management needs to focus on the patient- we need to use the main philosophies of case management:

Advocacy: Whether we case manage from a Practice or Managed Care Organisation, advocating for a patient is a delicate balance between ensuring the patient receives the treatment they want and the treatment that they can afford by way of benefit, resource use and evidence-based medicine. Using all this information we should be assisting the patient to make informed decisions and not waiting to expensive authorisations with hefty co-payments to be approved before discussing the implications with the patient. This is where Managed Care Case Managers and Practice Case Managers need to work together for the patient's common good.

Communication: Case Managers should be highly skilled communicators and able to assist patients by collaborating with Oncologists and motivating and empowering patients to make self-advocating decisions.

Case Managers should also ensure that they communicate with Oncologists with respect to the patient's benefits, limits and DSPs. This opens the channels of communication and negotiation ensuring that the patient receives the best, most effective treatment within their benefit limit, with the least financial cost to them.

Resource Management: Case Managers should be aware of, know how to use and have access to all the necessary resources

an oncology patient might need. They should also know how to authorise these resources, where they should pay from, which are PMBs and be able to advise and guide patients through this process.

Case Managers need to have the knowledge of protocols and all benefits to be able to help the patient find the right treatment and resources as the patients do not know the difference between palliative, hospice and adjuvant. It is a Case Managers job to ensure the patient makes not only sound clinical choices but sound financial choices too.

Education: Case Managers need to use education as a pillar of practice. All education should be done in an open, honest and simple manor. Ensuring both the patient and the patient's family understand the financial and clinical treatment pathways. This will ensure the patients adherence to treatment and help the patient make more informed and self-advocating decisions.

Educating Oncologists on the patients benefits and ensuring that the Oncologists know that the Case Manager is on the patient's side, open to discussion and approachable. This leads to teamwork in the patient's best interests.

Because a reasonable person would want to discuss cost it could be assumed that it is both the Case Manager and treating Oncologists' legal responsibility to discuss this with them. Today's oncology treatment is more effective and less toxic, but in the process, it is more expensive. Just like Oncologists and Case Managers are duty-bound to explain physical side-effects such as vomiting, nausea and neutropenia, they are just as responsible for warning patients about the financial side-effects of treatment that the patient is due to use.

Ensuring continuum of care and continuous interaction with a patient ensures correct use of resources and reduction in authorisation duplication. Early recognitions of warnings for possible arising problems, preventing lengthy hospital stays or readmissions. Correct authorisation upfront ensures correct payment at claims level ensuring fewer claims rejections and denials.

All these lead to happier and more satisfied patients, who adhere to their treatment. In turn, they stick within their benefits because they are educated and self- advocate for their financial benefit. This keeps the schemes more financially fluid.

Conclusion

Often when a patient is diagnosed with cancer, the immediate focus is on their medical needs. As treatment planning takes over, the patient can get lost. Unlike the medical and clinical side-effects that we, as Case Managers, help support the patient through, with medication and psychosocial referrals, Financial Toxicity is a devastating consequence that we often forget about and thus the patient and their family are often left to deal with it alone. This often leaves them frustrated and financially broken.

As Case Managers we need to step away from the computer and start advocating for our Oncology Patients and Oncologists in the correct benefits, limits and use of DSPs. We also need to educate other departments within our companies on the correct way to process Oncology and Oncology related accounts from the correct resources and benefits- including PMBs. This will cut down on unnecessary rejections and accounts referred to members to pay. We need to help patients ask the tough questions about their treatment so that they are educated, assist them with Patient and treatment Navigation and assist them with the reimbursement of their claims from the correct benefits by making sure everything is authorised from the correct benefits from the start.

As cancer gets more and more prevalent, drugs get more and more expensive and Medical Scheme schemes get more and more financially strapped, Case Managers and Oncologists are going to need to work together to ensure the patients get the best possible and most appropriate care while doing the least amount of damage to the patient financially.

The purpose of this study was to investigate the breakdown in communication between Medical Schemes, patients and Health Care Providers (Oncologists) with regards to benefits, limits, copayments and exclusions, leading to Out of Protocol requests and unrealistic treatment expectations on the oncology patient's part, ultimately leading to patient's financial toxicity. This has been shown to be due to Medical Schemes using Utilisation Management in place of correct and qualified Oncology Case Management creating a barrier to successfully advocating for the patient.

While there is no doubt Utilisation management is imperative in order to maintain and control cost burden within schemes, this study shows that it is evident that Case Managers are needed within the practices and the schemes where their jobs are:

- Educating patients on their condition, their treatment options and their scheme benefit limits and rules.
- To collaborate with schemes and Oncologists as well as other specialists involved in the patients care.
- To ensure the patient received multi-centric care, that is well authorised and resourced.
- These Case Managers should be able to review Treatment plans on a case by case basis as well and within the bounds of protocols and guidelines.
- Case Managers should be able to determine medical necessity and achieve savings while never losing sight on their main responsibility- the patient.

It is evident that South Africa needs to look at the way we case manage our Oncology patients, and this needs to start with educating our current Oncology Case Managers. Ensuring, that while the essential Utilisation Managers and clerical admin staff load plans within the practice and schemes, Case Managers, in both arenas are given time to actively work with oncologists and patients to ensure patient advocacy, education and support. This will not be achieved by authorising first and notifying patients of hefty co-payments later as it currently occurring, but by sitting with the patients and explaining the benefits, limits, co-payments and possible financial implications.

By taking the time to educate ourselves as Case Managers with the courses available to us (free oncology courses; international Patient navigation courses; National Case Management courses) and to learn to code correctly within the PMB boundaries set out by law.

We then need to assist the oncologists, collaborate, build trust and show knowledge and passion. In doing this we become the allies for the good of the patient rather than adversaries to the patient's detriment.

With these steps we can provide our oncology patients with thoughtful, passionate Case Management that will ensure that they are assisted and guided through the quagmire that is Oncology Case Management without the financial burden that they are suffering with currently.

As the population of oncology patients grows, physicians face increasing time constraints, and the cost of oncology treatment sky rockets, this only increases the role and value of a well-trained Oncology Case Managers who is willing to step up, advocate and collaborate with all the medical parties to ensure the patient receives the best treatment available to them.

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