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Investigating processes to support and improve informed financial consent in Australian cancer services: an implementation process mapping study and analysis

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ABSTRACT

Objectives Through implementation process mapping and thematic analysis, this study aimed to understand existing pathways of established informed financial consent (IFC) processes to develop general recommendations for implementing IFC in various cancer care settings.

Design Implementation science-based process mapping qualitative study. The Consolidated Framework for Implementation Research (CFIR) informed the development of interview questions and a process map outlining a normative process or workflow for patient consults was used during the interviews.

Setting Australian cancer care provider health services.

Participants Australian healthcare professionals who provide services to cancer patients and indicated having an IFC process or activities in their service were approached through existing networks to participate in a semistructured interview.

Results Ten healthcare professionals who regularly worked with cancer patients were interviewed. IFC processes varied by professional specialty (ie, general practice, surgery, radiation oncology and medical oncology) and healthcare settings (eg, public and private). An aggregated process map that highlights the key components of IFC processes discussed was created and includes strategies such as centralised points of contact, consolidated information delivery, reiteration of information by others or at various time-points and the use of follow-up appointments to revisit the financial impact of treatment. Interview themes identified barriers and facilitators such as training, resources and templates that to support or hinder IFC in accordance with CFIR domains.

Conclusions The themes and aggregated process map provide timely recommendations for healthcare professionals who provide services to cancer patients to facilitate IFC with their patients prior to treatment or as treatment changes. These practical actions will assist healthcare professionals and services providing cancer care to integrate IFC practices and processes into their routine patient interactions. Further work should identify implementation strategies to integrate and scale-up these evidence-based IFC processes and practices across the healthcare system.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This is the first study in Australia to comprehensively examine pathways and strategies used by cancer healthcare providers to achieve informed financial consent.
⇒ The use of implementation science process mapping to elicit barriers and facilitators of delivering informed financial consent is novel.
⇒ Further wide-spread research is needed, as participants in this study were largely working in the private health sector.

INTRODUCTION

Financial toxicity, often also referred to as financial burden, in cancer care is the negative patient-level impact of the cost of cancer.[1] It is the combined impact of out-of-pocket costs and the changing financial circumstances of an individual and their household due to cancer, its diagnosis, treatment, survivorship and palliation causing both physical and psychological harms, affecting decisions which can lead to poorer physical and psychological cancer outcomes.[2] Financial toxicity can be experienced at any time during the cancer journey and is often increased at diagnosis and during active treatment. It is experienced differently by each person and disproportionally affects people living in lower socioeconomic areas.[3 4]

The out-of-pocket costs associated with a cancer diagnosis vary significantly depending on the type and length of cancer treatment and ongoing care, and where people access their treatment even if treatment occurs exclusively in the Australian public health system.[5–7] Out-of-pocket costs for cancer care accumulate in addition to usual living expenses, often when people affected by

cancer and their families have reduced capacity to work in paid employment. Additionally, people are often not aware of the financial support programmes and access to support may not be straight forward meaning people miss out on financial support available to them. A recent systematic review on financial toxicity for people with breast cancer found the rate of experienced toxicity to be 78.8%.[8]

Cancer care involves multiple procedures and healthcare providers, with services often offered as public or private options in the Australian setting. For patients, being aware of and navigating these options can be challenging and can result in 'bill shock'.[2 9] 'Bill shock' is experienced when patients receive invoices for amounts higher than expected for cancer care services they have received.[2] It indicates that people affected by cancer are not fully aware of the out-of-pocket expenses related to their cancer care and the financial impact of their decisions prior to treatment, and they are making decisions without all the information available.[10]

Informed financial consent (IFC) is one strategy to mitigate financial toxicity, it involves the provision of cost information to patients, including notification of likely out-of-pocket expenses or gaps, by all relevant service providers, preferably in writing, prior to admission to hospital or treatment.[11] As well as being an ethical obligation underpinning good clinical practice,[12] IFC is a critical component of informed consent under the Australian National Safety and Quality Health Service Standards and is reviewed during health service accreditation assessments. It is critical that healthcare providers obtain meaningful IFC from patients before commencing treatment or entering into financial agreements[13] and consider the potential for financial toxicity as they obtain IFC.[12] However, without a standardised process or consistent cross-condition guidance requiring all healthcare providers to give cost-related information beyond a single interaction, it falls to patients to ask about costs directly. Patients are often embarrassed to ask about costs in fear of judgement or being offered different care or perceive that the costs of any recommended and necessary treatment will be covered by the public health system or their private health insurance (which is often not the case).[12] This can lead to patients missing out on crucial conversations about costs prior to treatment and not achieving IFC, and therefore potentially experiencing financial toxicity.

Financial toxicity in cancer care is an emerging issue and there is an immense need to improve existing and develop new IFC practices within the Australian healthcare system to both enhance consenting and avoid financial toxicity, encompassing both public and private cancer care services.[14] While there is no formal standardised process in place in Australia, healthcare professionals have a wealth of tacit, experiential and contextual knowledge that may be applied in the development of strategies to operationalise IFC.[15]

The aim of the study was to understand and document how IFC is obtained in different Australian healthcare settings where people with cancer are treated. Semistructured interviews and the use of implementation process mapping identified the barriers and enablers to IFC implementation across the patient treatment pathway in various healthcare settings. Objectives of this study sought to demonstrate how, and what it takes, to implement activities to support IFC as a routine process or procedure in cancer care and provide examples of practical applications and solutions for health services to use or adapt in their settings.

METHODS

Participant recruitment

Sample population and eligibility

Potential participants were healthcare professionals providing healthcare services to cancer patients in Australia who identified that they had an established process for IFC within their service. Specifically, potential participants needed to have knowledge of IFC processes in their setting, direct facilitation of IFC with patients and responsibility for IFC practices and activities within their setting. They were required to speak English and consent to a semi-structured interview.

Recruitment procedure

Potential participants were identified as they had either contributed to the development of the Standard for Informed Financial Consent,[14] self-reported their use of IFC processes to the Standard publishers following the launch, or were identified as early adopters of the Standard for Informed Financial Consent by professional organisations, patients or colleagues. A snowball sampling approach was then taken.

Based on the experience of developing the Standard for Informed Financial Consent, a small sample size (~8–12 participants) was expected.

Potential participants were emailed an invitation to participate in this study. If no response to the invitation email was obtained after 1 week, a follow-up email was sent. A final follow-up email was sent 2 weeks after the initial invitation email. The invitation email included the participant information sheet and consent form.

Informed consent and ethical approval

Invited participants were asked to return the consent form prior to undertaking an interview. All participants provided their informed consent.

Semistructured interviews

Study involvement included one semistructured interview that took up to 1 hour, conducted through the Microsoft Teams videoconferencing platform. Participation was voluntary and no incentives were provided.

Interviews were audio recorded and transcribed by a third-party transcription service. All interviews were completed by the project lead (RC).

Building on work using implementation process mapping to capture and explore variability in clinical practice,[16] the interview consisted of two components: (1) questions regarding existing IFC processes to explore barriers to and enablers of obtaining IFC, guided by the Consolidated Framework for Implementation Research (CFIR)[17] and (2) implementation process mapping exercise.[18] While these components are separate, they were addressed during the interview according to the flow of discussion.

CFIR-guided questions

The CFIR is a comprehensive framework for characterising contextual determinants of implementation.[17] It includes 39 constructs organised into five domains (Innovation Characteristics, Outer Setting, Inner Setting, Characteristics of Individuals Involved and Process). It is used to systematically assess potential barriers and facilitators in preparation for implementing an innovation.

Interview questions in this study were developed with the guidance of the CFIR framework, considered against the participant profiles (eg, type of healthcare professional) and were adapted for relevance. The interview schedule was piloted with test participants prior to being finalised. The final interview schedule is available in online supplemental appendix A.

Implementation process mapping

Process mapping is a tool used in implementation science to elicit current ways of working and highlight areas in which a certain procedure and/or intervention(s) can be more effectively integrated to improve quality.[18,19] In this study, a process map (online supplemental appendix B) was developed that depicted the generally standardised process of how cancer patients progress from initial referral to the healthcare professional through to treatment and follow-up. This was used to guide questioning and ask participants to highlight where throughout the normative workflow of a patient consult IFC was discussed and obtained. An individual process map of current service delivery methods for each participant was designed based on the interview responses. Individual process maps were then aggregated to form a conceptualised process map that sets out general recommendations for strategies used to obtain IFC.

Data analysis

Interview transcripts were analysed utilising a deductive framework methodology guided by the constructs of the semistructured interview guide.[20] A coding tree was developed that identified common responses or themes from the interviews under particular areas of interest as determined by the interview guide. We identified barriers and facilitators/intuitively designed implementation strategies for IFC in each clinic/practice. Barriers were coded to CFIR domains. We matched barriers and identified intuitively designed strategies for obtaining IFC. We then coded these identified intuitive strategies to strategies identified in the Expert Recommendations for Implementing Change (ERIC) taxonomy.[21,22] The CFIR and ERIC are commonly used in conjunction with each other as ERIC strategies are matched based on CFIR identified barriers and enablers. Transcripts were subjected to thematic analysis applying the five stages of framework methodology.[20] (1) Familiarisation with interview data: all study interview transcriptions were revised for accuracy from third party transcribers (RC, CM and EK). (2) Identifying and creating a thematic framework: all transcripts were independently analysed and discussed with the study team. Through team consensus, a preliminary coding framework that organised data was developed; (3) Indexing: utilising the existing framework, all interview transcripts were coded accordingly (by CM and EK). Any novel themes were discussed with the study team; (4) Charting: themes and supporting quotes were documented using an Excel matrix and (5) Mapping and interpreting: the framework was assessed for consistency and rigour across themes.

RESULTS

Of the 20 healthcare professionals invited to participate, nine did not respond, and an appropriate interview time was unable to be scheduled for another. Ten participants completed semistructed interviews. On average, interviews lasted approximately 50 min (range 35–75). The majority of participants were from New South Wales (n=6) and represented the experiences of private healthcare professionals (n=6); however, alternative perspectives were also obtained. Table 1 presents the type of

Table 1 Participant representation

Interview	Type of practitioner	Service delivery/location type
1	Medical oncologist	Public and private clinics—New South Wales
2	General practitioner	Private practice clinic—Victoria
3	Radiation oncologist	Public clinic—Queensland
4	General practitioner	Mixed billing clinic—New South Wales
5	Medical oncologist	Private clinic—New South Wales
6	Radiation oncologist	Private clinic—New South Wales
7	Surgeon	Public and private tertiary hospital—Victoria
8	General practitioner	Mixed billing clinic—New South Wales
9	Surgeon	Private hospital—New South Wales
10	Radiation oncologist	Private hospital—Western Australia

Table 2 Coding identified CFIR barriers, intuitive facilitators and strategies and associated explicit ERIC strategies

Identified barrier	Brief definition	CFIR domain	CFIR subdomain	Intuitive IFC strategy	ERIC-coded strategy
No method to screen for financial distress	Clinicians stated that they were not aware for specific validated tools to use clinically that screens for financial distress.	Inner setting	Readiness for implementation	Appoint a dedicated financial officer	Identify and prepare champions
No templates, resources or guidelines for implementing IFC processes	Some clinicians detailed that they are not aware of any existing national approaches or templates, resources or guidelines on how to implement an informed financial consent processes in their clinic/practice.	Outer setting	External policy and incentives	Providing cost transparency with IFC resources for patients	Develop and organise monitoring systems
Lack of formal training on providing financial disclosures	Clinicians discussed that they have received no formal training on how to initiate and discuss patient finances as part of their medical training	Characteristics of individuals	Self-efficacy	Integration of IFC as part of clinical discussions	Develop a formal implementation blueprint

CFIR, Consolidated Framework for Implementation Research; IFC, informed financial consent.

healthcare professional, classification of their service delivery type and location.

Factors influencing implementation of IFC processes

Factors influencing implementation were coded as either barriers or facilitators/strategies to the process of IFC. Barriers were defined as challenges or hinderances to obtaining IFC, and facilitators or strategies were defined as things or actions that might help to obtain IFC. Table 2 displays the coding framework of barriers and any associated identified intuitive facilitator/strategy, as we deductively coded to the CFIR, not all domains of the CFIR are represented. Intuitively designed implementation strategies were also coded to explicit ERIC strategy (table 2) facilitators identified.

Barriers

The lack of formal guidelines and processes to aid in the delivery of IFC was identified as a major barrier to IFC. Three main areas were described by participants.

Unawareness of methods to screen for financial distress

Half of the participants were not aware of formal ways to screen for financial distress to understand patients' levels of concerns/worries about their monetary commitments and responsibilities.

> I am not aware of a formal way to screen for that kind (financial) of distress. Other than just asking, as part of a visit or consult, but some (clinicians) aren't used to having to do that. (Interview 7)

The majority (n=7) of participants had their own procedures for discussing financial distress as part of either initial consultations or during a follow-up consultation; however, none used a standardised measure to capture financial distress.

Lack of formal training to provide financial disclosures

All participants expressed having never received formal training on how to initiate and engage in conversations about a patient's financial capacity nor were they aware of any opportunities to engage in this type of training.

> The idea of prudent financial management of your personal finances, for example, or financial disclosure with patients, they're not topics that are prescribed in any training course. (Interview 10)

Some participants suggested that this training should be embedded into medical or registrar training curriculum. Some discussed how clinicians mainly derive these communication skills through role modelling of their mentors. If they were training under someone with an established process for discussing finances, this element of consultation now also become informal knowledge for the trainee.

> Our big question should be how do we train registrars coming out right now? And the reason I say that is, once you start practice, if you don't have that philosophy of care of financial consents built in, it's almost a bit late, unless someone teaches you or the person you are working under has their own process for you to learn from. (Interview 1)

Unaware of templates or resources to guide development of IFC processes

Participants were unaware of available resources or templates to guide development of IFC processes in

individual health services. As 'early adopters' of their own IFC processes, while they did not use any formalised resources, they had intuitively developed their own to help patients navigate financial complexities.

> I'm not aware of resources, other than the ones we have made to use in our practice, that are freely available or encouraged for use to make sure informed financial consent is obtained. (Interview 10)

Facilitators and strategies

Common strategies as to how IFC processes could be supported and achieved emerged from the interviews and these were included within the aggregated process map.

Dedicated financial officers

To overcome perceived informational overload for patients, several participants identified a centralised role within the health service to be the main point of contact for all financial queries and further discussions.

> Someone needs to be the contact person. I don't think that should be the specialist. We (the health service) thought it sat better with someone else who has more time to really go through financial options. So we have a financial officer who is the point of contact for those conversations. (Interview 1)

These 'financial officers' were often the administrative staff or managers of the health service. These contacts help patients understand the costs involve, navigate the Medicare rebate system and aid patients in enquiring about their private insurance coverage, if relevant/needed.

Integration of IFC as part of clinical discussions

All participants agreed that it is the clinicians responsibility to initiate cost discussions, even if they are not the ones with all the relevant in-depth information. They deemed it important for patients to be introduced to the topic of finances from their clinician to build trust and maintain transparency.

> We (clinicians) should all be comfortable with having financial conversations with patients. I, myself, find that initially when I started, that the first barrier was myself, we are not trained to have financial conversations. But it's up to me (the clinician) to be the first one to tell my patients what to expect both clinically and in this case (financially). (Interview 10)

Providing cost transparency with IFC resources for patients

A common practice by participants was to provide patients with a physical copy of a breakdown of costs. This was either done electronically or printed versions.

> We (health service) provide them with an informed financial consent document and on that document is the name of the procedure, the item numbers of the procedure, and then the fees associated with it and the rebates that we calculate they will receive and therefore at the bottom line, what their expected gap (out of pocket costs) will be depending on their level of insurance, and so we give that to patients beforehand, before they confirm (treatment). (Interview 9)

One participant provided their base costs for services on their website. The reason for displaying costs of services online was to show clearly the gap that people would pay.

> That's what really drove it (putting costs for services online), was because we realised there's a gap (between what Medicare covers and what we charge), and there's nowhere that explains it properly. The government doesn't explain it properly, and I understand that, but there's nowhere really that you can see it explained properly. So we placed our fees online for transparency as so that there is no questioning or shock from patients. (Interview 10)

Aggregated process map

Based on interview data and identified existing strategies identified by the Standard for Informed Financial Consent and associated resources for IFC processes, an aggregated process map was developed to provide recommendations on practices to support IFC.

The process map is set within the context of a patient's journey and interactions with healthcare professionals providing cancer care services. The map (figure 1) illustrates commonly used strategies to support IFC across four core phases of this journey: referral/scheduling of initial appointment, appointment attendance, treatment and follow-up and recurrence (as relevant). Throughout the process, commonly used strategies to obtain IFC were noted and are presented as recommendations.

DISCUSSION

This study details the existing pathways of established IFC processes and the strategies used by healthcare professionals to achieve IFC in their clinics and provides general recommendations for implementing IFC into various cancer care settings. The themes and aggregated process map identify the potential strategies to support IFC alongside patient interactions with their healthcare professionals. While these strategies are aimed towards health services and individual healthcare professionals, outcomes from this study indicate opportunities for further scale-up of initiatives to enable a consistent approach to IFC across the healthcare system. With this focus, all people affected by cancer could be provided the opportunity to discuss costs and the financial implications of cancer treatment and care.

All participants agreed that at the outset, it is the healthcare professional's responsibility to initiate discussions about cost and financial concerns, even if they are not the ones who will provide all the relevant in-depth information, a view also reflected in similar studies.[15]

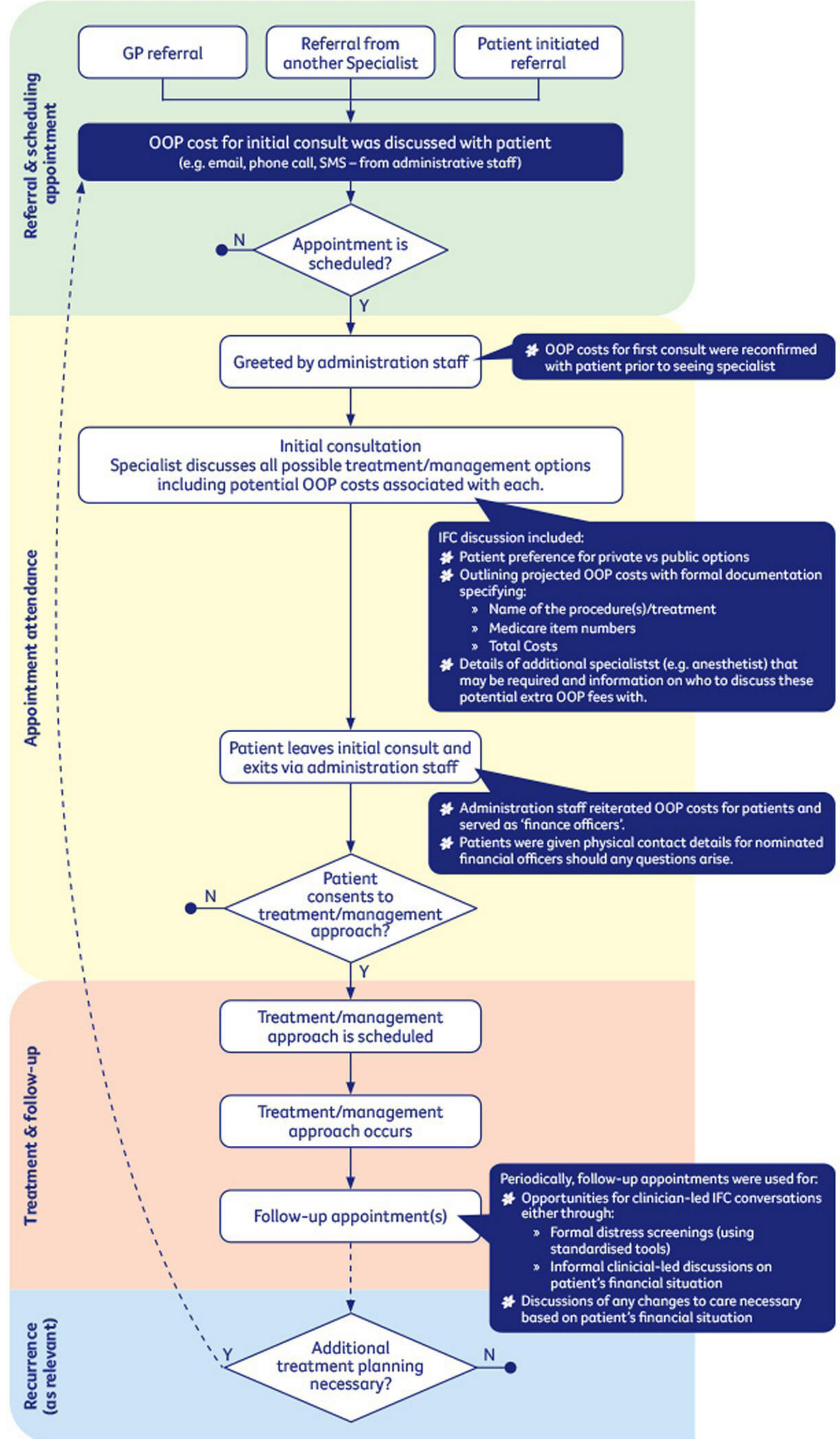

Figure 1 Aggregated recommendations from early adopters. Call out boxes indicate critical points along the process where general recommendations of informed financial consent intuitive and theory-driven strategies can be deployed. GP, general practitioner; IFC, informed financial consent; OOP, out-of-pocket; SMS, short message service.

Although many healthcare professionals feel confident in having discussions about cost and that discussing financial concerns is a key component of high-quality care, the ad hoc nature of these conversations and focus on certain components, commonly medicines and services not listed on the Pharmaceutical Benefits Scheme and Medicare Benefits Schedule, leaves some patients without knowledge of the extent of costs or available financial support to them.[10 15] Healthcare professional and healthcare delivery organisations have incorporated IFC into their resources and guidance documents to promote this conversation. However, in some settings, there remains a focus on the patient initiating conversations about cost which is contradictory with recent literature and the views of the healthcare professionals within our study. Where a standardised solution is not available, healthcare professionals regularly adopt on the spot strategies to address individualised challenges to patient care. In identifying these intuitively driven strategies, we aimed to recognise the tacit knowledge of healthcare professionals to solve these challenges. Coding these intuitive strategies to the ERIC taxonomy allowed for potential replication through an implementation science approach to be considered and tested in other settings.[22]

This study identified several enablers to conversations and IFC, including employing strategies such as identifying a specific individual to be the contact person for questions around treatment and care costs. While this strategy was discussed in detail by participants in this study, participants who had access to a dedicated contact person continued to maintain the importance of the healthcare professional being the one who instigates the discussion with patients in the first instance. This enabler reflected service level capacity, and that not all clinics will have resources available to have a dedicated individual for this purpose. Where they are available, due to scale and patient volume, dedicated financial officers provide a centralised point of contact, can reduce informational overload for patients and offer support the integration of IFC into clinical discussions. Providing patient navigation such as this has been highlighted as a potential strategy to mitigate financial toxicity.[23 24] While healthcare professionals have a strong bond of trust with their patients and can initiate conversations about cost and IFC, this study supports the requirement that additional resources to explore the complexities of costs and provide resources to patients (such as physical quote covering costs or displaying cost information on clinic websites), are essential to achieving IFC in cancer care. Participants in this study acknowledged the importance of reiterating costs and cost information throughout cancer treatment and care, and of using follow-up appointments to revisit potential financial burden and in follow-up. This raises the need for a standardised screening tool that can be used across the healthcare system and emphasises the importance of continuing with cost discussions if and as additional treatment is required.

While other studies and advocacy papers have suggested mitigation strategies for financial toxicity such as changes to insurance design and routine screening of financial distress,[24] this paper focuses on intuitive strategies to obtain specifically obtain and ensure IFC, which in itself is a further strategy to lessen the experience of financial toxicity. Major barriers to IFC identified by healthcare professionals in our study reflected limitations of the support available to them in the broader health service and health system. Individual healthcare professionals with IFC processes in place were proactive in adopting strategies to overcome these limitations where they had capacity. Although discussing costs and financial concerns are often inter-related, the different approaches to addressing these, depending on the capabilities and information available to the healthcare professional, demonstrate the importance of a health system which considers financial navigation with the linking of clinical, social and supportive care services.

The Australian Medicare Review Taskforce has recognised the importance of the need for more centralised strategies to support cost transparency and understanding of medical out-of-pocket costs within the context of the complexities of the multipayer system in Australia. Further to this, access to financial support to reduce the financial burden of a cancer diagnosis is needed by expanding the availability of financial counsellors to improve access to this resource for people affected by cancer.

While there are opportunities for individual healthcare providers and services to implement activities that support IFC, at a systems level, the development and implementation of a consistent documented procedure with appropriate provision of information to assist providers in explaining costs to consumers prior to a course of treatment would significantly set the platform and expectation for all in the health system to follow to ensure consistency for all people affected by cancer. Further work must consider how the healthcare system can ensure that all people affected by cancer are supported and provided the opportunity to discuss costs, know their options for treatment and care and understand the potential financial implications of their cancer diagnosis. Challenges to IFC can be overcome with a commitment from the healthcare system, healthcare services and healthcare professionals recognising the impact of cancer on people's financial situation and enabling agency in decision making.

Strengths and limitations

Strengths of this study lie in its comprehensive examination of established pathways and strategies used by healthcare professionals to achieve IFC. The findings offer general recommendations for implementing IFC in various cancer care settings, addressing the need for consistent and proactive discussions about costs and financial concerns. Our findings highlight the importance of healthcare professionals initiating these conversations, but in order to do so, resources and practices that enable these conversations to occur are pivotal (eg, a templated IFC form that outlines cost expectations).

However, a limitation of this study is the small sample size and the majority of participants being from New South Wales and private healthcare professionals. This homogeneity of the sample certainly limits the generalisability of the findings to other healthcare settings and populations. Additionally, there are several underserved populations in Australia (eg, culturally and linguistically diverse peoples, and Aboriginal and Torres Strait Islanders) of who's perspective on the issue of IFC and the larger problem of financial toxicity could not be understood through this specific project and further research is imperative. Despite this limitation, the study's methodology and data analysis guided by established implementation science frameworks, strengthens the validity and reliability of the findings within the specific context examined. The careful selection of participants with established IFC processes allowed us to gain insights of intuitive strategies already in current use to ensure IFC and contribute to a decrease in financial toxicity. The strategies that are highlighted would be useful for healthcare systems with a similar context of public and private pay systems. The in-depth exploration through semistructured interviews and implementation process mapping provide robust insights into the factors influencing IFC implementation in cancer care. Nevertheless, future research with larger samples including clinicians from a broader range of settings would further enhance the generalisability and applicability of the findings to a broader healthcare context.

Conclusion

This study provides several recommendations for how IFC can be facilitated in cancer care settings and enabled at a standard considered quality by the healthcare professional community. Successful implementation requires support from both the broader health system and individuals providing cancer care to patients.

The provision of information to support IFC, is multifaceted, initiated by the healthcare professional, supported by the health system and a process which enables consumers to feel as though they can ask about costs and their options without embarrassment or fear of being treated differently.

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