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1. Introduction

Worry about affording medical care is highly prevalent among Americans (Weissman et al., 2020). About 60% of Americans stress about costs of health care and medications and/or medical bills including unexpected bills, and more than 50% worry they will not be able to pay for the health care services they may need in the future (American Psychological Association, 2018, American Psychological Association, 2019, Montero et al., 2022). It is also common to see media stories highlight exorbitant medical bills and medical debt that patients face. For example, a 2020 news article reported "on the verge of being intubated and put on a ventilator, the person [a COVID-19 patient] "gasped out" the question, "Who's going to pay for it?" to their medical team" (Mahbubani, 2020). All medical conditions have economic consequences that result from the costs of medical care and treatment, other expenses indirectly related to care such as traveling to access doctors and care facilities, and potential loss of income (Pisu et al., 2018). The scientific literature over the past 10 years has defined and reported on medical "financial hardship" which refers to distress and difficulty in paying medical bills and accessing or using recommended medical care due to cost (Altice et al., 2017). Now, there is increased awareness of "financial toxicity" as a side effect of medical treatment equivalent to other physical toxicities such as nausea, pain, or fatigue (Zafar and Abernethy, 2013). In the United States, it is estimated that 137 million adults experience some form of medical financial hardship, including 28% of adults 65 and older and almost 47% of younger adults (Yabroff et al., 2019), across a spectrum from relatively manageable related distress to catastrophic expenses with medical debt being the number one cause of bankruptcy (Hamel et al., 2016).

Medical financial hardship is associated with worse mental and physical health, and leads to behaviors such as forgoing medical treatment and delaying health care that can be detrimental to health (Altice et al., 2017, Yabroff et al., 2019). However, its full impact on well-being has not been fully investigated yet. In particular, there is a great need to understand how medical financial hardship across its spectrum affects individuals emotionally due to notable and common increases in stress, depression, worry and other negative emotions that may result from such hardship (American Psychological Association, 2018, American Psychological Association, 2019, Montero et al., 2022, Barbaret et al., 2019, Chan et al., 2022). Similarly, there is a need to understand how these emotions and stress impact health outcomes (Cohen et al., 2012, Irwin and Cole, 2011, Diefenbach M et al., 2008, Pressman and Cohen, 2005, Pressman et al., 2019, Boehm and Kubzansky, 2012, Ryff and Singer, 2008). Moreover, while there is growing research on the negative effects of financial hardship, much less is known about what to do to help with this issue. In cancer and other illnesses, patients manage the financial and emotional aspects associated with the economic burden of disease using strategies that can be problem- and/or emotion-focused (even while insured) (Head et al., 2018). It is necessary to understand the broader impacts these strategies have on patients and families. Similarly, interventions may be needed at community, health system, and policy levels to prevent medical financial hardship and its impact on well-being.

To advance knowledge in this area, the Emotional Well-Being and Economic Burden (EMOT-ECON) Research Network was funded to spearhead research and develop new insights about the impact of economic burden of disease on emotional well-being, with the ultimate goal of developing the strategies needed to reduce such impact. It is one of six research networks funded by National Institutes of Health (NIH) agencies to advance research about emotional well-being. Recently, emotional well-being has been defined as a multi-dimensional composite that encompasses how positive an individual feels generally and about life overall, including both *experiential* features (emotional quality of momentary and everyday experiences) and *reflective* features (judgments about life satisfaction, sense of meaning, and ability to pursue goals that can include and extend beyond the self) (Park et al., 2022a). The economic burden of disease leading to medical financial hardship has the potential to impact both of these features. To guide its work, a Strategic Planning Meeting was convened virtually in October 2021, and an in-person Scientific Meeting was convened in January 2023. The goal of these meetings was to bring together diverse stakeholder groups from academic and other institutions across the US including researchers studying medical financial hardship and/or emotional well-being, patients and patient advocates, and health care providers, to guide ongoing and future work in these intersecting domains. This paper summarizes key discussions and recommendations from these meetings to inform the directions and priorities in the study of the economic burden of diseases and emotional well-being and future work of the EMOT-ECON network.

defined limited time points, e.g., over the past week or month, and miss the measurement of longer-term or chronic financial hardship, which may have different impacts on emotional well-being and health.

3.2 Mechanisms

Before discussing the mechanisms by which the economic burden of disease affects patients' emotional well-being, participants discussed at length what influences whether the economic burden of disease becomes a stressor. First, participants discussed a hallmark of this stressor, the extreme uncertainty and unpredictability, compared to other financial stressors that may be more predictable, such as regular bills and expenses. The following characterize the economic burden of diseases:

a) Unknown amounts of out-of-pocket expenses for medical care, even when patients are insured,
b) Unknown timing of medical bills, including when patients are billed and when they should pay the bill;
c) Unknown consequences of being unable to pay medical bills and worry about being unable to access needed treatment.

It was recognized that patients and their families may have varying baseline financial skills or self-efficacy to problem-solve when faced by these kinds of uncertainty.

Second, attendees identified the difficulty of dealing with financial issues as a specific and related stressor. Patients may have difficult and stressful interactions with insurance companies and health care billing offices, and may face the threat of having medical debt turned to collection agencies. These interactions add stress even at low levels of economic burden.

Participants then discussed how research should investigate the extent to which the economic burden of disease is perceived as a stressor across life circumstances. For example, this may depend on when the disease occurs during the lifespan, levels of available family or other support, cultural belief systems, socioeconomic status, or other social determinants of health. Given these varying circumstances, there may be a differential impact on the experiential and reflective components of emotional well-being described above (Park et al., 2022a). Similarly, the extent to which economic burden of disease is perceived as a stressor may depend on disease prognosis and curability, which affect how patients prioritize health care in relation to the costs of care, and impact amount and duration of medical expenses and ability to work. Moreover, the extent to which economic burden of disease is perceived as a stressor may differ depending on aspects of the economic burden of disease, e.g., whether patients face high out-of-pocket expenses for care but no job loss vs. low or no high out-of-pocket costs of care but job loss.

With respect to mechanisms by which the economic burden of disease affects emotional well-being, participants discussed the role of what people do to deal or cope with the burden. First, upon reviewing the strategies listed in the conceptual framework, it was recognized that some of them have positive or negative effects on emotional well-being and health. For example, a problem-focused strategy cancer patients commonly adopt is to forgo medical care or to skip prescribed medications to reduce costs (Head et al., 2018). This may have negative consequences for disease progression and health, but it may also impact emotional well-being directly as patients may be acutely aware that this strategy is detrimental to their health. Second, attendees recognized that experiencing emotions such as anger or sadness may be appropriate responses to this burden, and thus contribute positively to emotional well-being. Third, participants discussed the importance of investigating differences in coping strategies and their positive and negative effects for patients with different socioeconomic status or living in different contexts, for example patients living in poverty or rural areas.

Lastly, participants discussed valuable areas of research to understand factors that could moderate the impact of economic burden of disease on emotional well-being. In particular, those discussed were: i) comfort with uncertainty, ii) literacy (health literacy, numeracy, insurance literacy, etc.) and the ability to understand costs and manage other personal economic challenges; iii) resilience; iv) personal empowerment in interacting with different medical and non-medical professionals to navigate financial hardship; v) available resources such as support or insurance; and vi) living context that may be characterized by existing policies or type of health care system, i.e., for example a system of universal health care coverage.

3.3 Prevention and Intervention

costs, increase the ability to pay, reduce administrative burden, and raise awareness, education, and training about financial hardship for patients, caregivers, and the workforce of health care, financial and other institutions. Attendees also recognized that these efforts need to go hand in hand with interventions to strengthen mental health, tailoring them to meet patients where they are mentally and financially, so as to provide the best chance of successfully reducing the impact of economic burden. Attendees supported screening for financial hardship, but also for anxiety and depression, recognizing that patients with mental health problems may be less able to deal with practical and financial problems. They also supported financial navigation and coaching in health care and other systems, as well as strengthening peer support to address economic burden.

Discussions for tertiary prevention to manage poor emotional well-being resulting from economic burden of disease and prevent exacerbations and complications reflected on the effects of economic burden and the strategies to deal and cope with this burden reported in Table 1. Participants proposed strengthening mental health workforce and support with interventions to address clinical depression, to target positive affect and also to promote a more holistic, eudaimonic well-being that incorporates meaning and purpose (Ryff, 2017). Moreover, participants discussed the need to support caregivers facing burnout and helplessness.

5. Conclusion

Researchers, patients, health care providers, patient advocates, and other stakeholders, bring unique perspectives to the task of understanding the impact the economic burden of disease on emotional well-being and ultimately on health. This cross-disciplinary lens made for unusually energizing and creative discussions at the Strategic Planning and Scientific meetings of the EMOT-ECON network, attesting to the unique value and power of this approach. Overall, although not an exhaustive list, participants identified some important future areas of research, which included: i) aspects of emotional well-being relevant to patients experiencing economic burden of disease and financial hardship, both in terms of what are prevalent and relevant emotions, and how the broader outlook on life is impacted; ii) constructs and contexts that may influence, or protect from, perceiving the economic burden as stressful; iii) ways in which patients deal or cope with the medical financial hardship across different contexts and populations with positive or negative effects on emotional well-being and health; and iv) interventions at multiple levels and from multiple stakeholders that address economic factors (e.g., costs, ability to pay), administrative burdens, education and training, and especially patient's emotional as well as financial status.

Discussions at these EMOT-ECON meetings and the updated framework align with current research on financial hardship. For example, recent research has started to recognize the complexity of such hardship which is not only due to high costs of care or reduced ability to work and earn an income, but to uncertainty and the difficulty of dealing with financial issues. Cancer patients in Gharzai et al. described the impact of having limited knowledge of the treatment course, of the costs and work limitations to be incurred, and the financial adjustments patients make through treatment (Gharzai et al., 2021). Lyman and Kuderer discuss the "abuse" and "torture" associated with dealing with the health care system when patients are not able to meet financial responsibilities, especially for the most vulnerable patients (Lyman and Kuderer, 2020). In a German population with a different health care system from the US, Lueckmann et al found that bureaucracy had a significant impact on whether patients experience financial distress, with patients feeling helpless due to time-consuming and complex processes, incomprehensible decisions by authorities and agencies, and lack of knowledge about rules and regulations when dealing with these entities (Lueckmann et al., 2022). Thus, as emerging from the EMOT-ECON meetings, future areas of research may include the investigation of personal characteristics like comfort with uncertainty, empowerment in dealing with financial issues, or literacy (e.g., health literacy, health insurance literacy, numeracy), and their role in how patients deal with the characteristics and components of the economic burden of disease, how they cope, and what the effects of that coping are on emotional well-being. The need to maintain focus on structural problems (cost of healthcare, insurance bureaucracies) is also key going forward.

The strategies identified in our meetings to deal and cope with the economic burden of disease build on those identified in previous literature (Head et al., 2018, Banegas et al., 2019, Kayser et al., 2021). Several frameworks recognize the potential negative impact of creative but medically non-advisable problem-focused strategies like lower adherence to treatments, delayed or forgone care (Altice et al., 2017, Lentz et al., 2019,

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Human Rights: This article does not contain any studies with human participants performed by any of the authors.

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Table 2: Some potential prevention interventions identified in roundtable discussions at the Scientific Meeting of the EMOT-ECON network (Memphis, TN, January 2023)

Levels	Primary Prevention Interventions To prevent the economic burden of disease from becoming a stressor	Secondary Prevention Interventions To prevent an impact of financial hardship on emotional well-being
Society/ Community	Early education through schools or media awareness campaigns on: - Costs of care and financial toxicity - Financial education and financial literacy - Health insurance - Emotion-based coping Employment of financial coaches in banks, insurance companies, and other institutions, with training in costs of care and medical debt	Education on insurance literacy and costs of care for patients and caregivers Personal financial coaches in hospitals/clinics Establishment of programs in financial institutions to train employees to help people with severe disease manage overall debt (medical and not).
Policy	**Insurance:** Universal healthcare; Revisiting health insurance benefit/policy to design coverage that minimizes patient burden; Health insurance reform including elimination of premium increases during illness, establishing disease specific out-of-pocket maximum, covering certain conditions fully, offering Medicaid supplements after reaching out-of-pocket maximum regardless of personal resources; Close coverage gap for Social Security Disability Insurance and Medicare. **Income-related**: Guaranteed income during severe illness and for clinical trial participation; Employment protections; Automatic eligibility for disability for specific diagnoses without burdensome eligibility process and automatic renewals. **Pharmaceutical companies:** Policies to lower costs of drugs; Drug price policy reform. **Research**: Funding for research to gain evidence for policy change.	**Insurance:** Ensure coverage for mental health.
Health care system	**System-level changes**: Costs: Reduced operation costs; Provision of transportation and more local services to decrease travel costs; Implementation of institutional simplification to reduce administrative burden. **Care:** Standardized provision of information on support systems and expected cost estimates early in treatment; Mental health: Establishment of screening for depression and anxiety as patients with mental health problems may be less able to deal with practical and financial problems **Workforce**: Establishment of financial navigation/counseling; Increased providers' awareness of economic burden of disease and of resources available to help patients; Creation of medical school curricula to raise awareness about costs of care **Patients**: Patient education on asking questions about resources, Removal of stigma	**System-level changes**: Establishment of universal screening for financial issues and risk of job loss; Systematic queries of social needs and screening patients based on available metrics at the institutions, i.e., prior use of financial assistance or payment plans, debt with institution, high utilization of ED; Establishment of a stratification system for people who need more or less intervention support; Establishment of workflow to deal with crisis, i.e., for patients with severe financial distress. Optimization of follow-ups and referral to available resources post financial hardship screening; Reducing administrative burden, and wait times while improving referral systems; Consideration of billing pauses and billing forgiveness tied to payment; Lower patient costs/fees; **Care**: Provision of consolidated care to reduce costs and address all patients' needs; Provision of treatment plans that include costs; Interventions based on patient's profile and/or previous history of mental and financial stress Ensuring patients are comfortable accessing provider care team (doctors, navigators, etc). **Workforce**: Provision of training on cost conversations; Establishment and training of financial navigators or coaches. **Patients**: Establishment of support groups with patients with financial hardship experience or training existing support groups to talk about costs of care and financial hardship; Education on disability benefits; Informational support to stop avoidance behaviors like ignoring payments due; Financial and insurance literacy training; Education for caregivers.

Figure 2.JPEG