

The role of personal social networks in supporting patients with chronic diseases to access outpatient clinics in Mbeya, Tanzania: A mixed methods study

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ABSTRACT

The increasing prevalence of non-communicable diseases (NCDs) in Tanzania and the inequitable provision of NCD care drives patients to seek support from their social networks. We studied a sample of patients with NCDs attending outpatient clinics to understand how informal social support helps patients with NCDs in coping with their illness, and whether it is associated with patients' engagement in care. We used mixed methods to analyse data from a client exit survey implemented in outpatient clinics in Mbeya, Tanzania in 2022. The quantitative analyses of data on 108 patients was complemented by qualitative analysis of in-depth interviews conducted on a sub-sample of 30 participants. Most patients faced difficulties completing work and household activities, creating a need for financial support. Expectations of reciprocal intergenerational support led patients' children to be the dominant providers of financial support. Participants' social ties frequently provided financial support, while emotional and informational support were provided to a lesser extent. Informal social support fills gaps in social health protection schemes and promotes engagement in care by providing patients with the means to finance uninsured costs of care. Expanding old age social security or other resource pooling mechanisms could reduce the susceptibility of patients and their support networks to catastrophic health expenditure, even for those with health insurance.

1. Introduction

NCDs are an increasingly significant contributor to the global burden of disease, now contributing to 71 % of deaths worldwide (Bigna and Noubiap, 2019; Gyasi and Phillips, 2020). Alarming, 82 % of these deaths occur in LMICs, underscoring the urgent need for effective prevention and management strategies in these regions (Bigna and Noubiap, 2019; Gyasi and Phillips, 2020).

Within this broader context, SSA, and Tanzania in particular, grapple with unique challenges in providing adequate care for NCDs. Patients affected by NCDs in these regions often encounter significant obstacles when accessing NCD care, as health systems in these regions are still contending with the complexity of financing and delivering chronic care

services (Adinan et al., 2019; Mwangome et al., 2017). Moreover, primary care facilities, typically the most accessible health care providers for Tanzania's predominantly rural population, are frequently inadequately equipped to provide effective NCD care, compounding the challenges faced by patients (Peck et al., 2014; Wineman et al., 2020).

As a result, patients seeking services or medications for NCDs frequently resort to self-referral to hospital outpatient care after facing difficulties accessing care at closer primary- and secondary-level facilities (Francetic et al., 2021; Makene et al., 2022). Despite primary facilities accounting for approximately 85 % of facilities in Tanzania, NHIF claims data indicate that 83 % of claims for NCDs come from hospitals (Hooley et al., 2021). This disproportionately high demand for hospital-based care reflects the perceived inadequacies in quality and

Abbreviations: CLD, causal loop diagram; IDI, in-depth interview; KI, Key informant; LASA, Longitudinal Aging Study Amsterdam; LMIC, Low- or middle-income country; NCD, non-communicable disease; NHIF, National Health Insurance Fund; ODK, Open Data Kit; RA, research assistant; SSA, sub-Saharan Africa; USD, United States Dollar; WHO, World Health Organization.

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availability of care at primary and secondary facilities (Adinan et al., 2019; Peck et al., 2014).

Furthermore, the costs of accessing hospital-based care can be substantial for people living in rural areas, becoming a substantial barrier to engagement in care and, at times, pushing patients further into poverty (Nyaaba et al., 2020; Nielsen et al., 2017). However, cultural practices of intergenerational care and informal social support can mitigate the burden on individual patients to a certain extent, so that patients do not bear the weight of these costs alone (Adonteng-Kissi et al., 2022; Amoah and Adjei, 2021). In this case, being engaged in care includes regularly visiting a health facility, receiving prescribed medicines, and taking those medicines.

While most patients with NCDs who seek care at health facilities in Tanzania are NHIF beneficiaries, there is some evidence that their personal social networks often provide additional financial support. This support becomes crucial in overcoming non-medical costs associated with seeking care, such as transportation expenses, which are not covered by health insurance benefit packages (Mwangome et al., 2017; Dowou et al., 2023; Hooley et al., 2022; Oyando et al., 2020). However, the rising prevalence of NCDs may threaten the sustainability of these informal caregiver support networks, as the financial strain of supporting older loved ones with NCDs may soon surpass the means of informal caregivers (Kpessa-Whyte, 2018; Twum-Danso Imoh, 2022).

To explore the intricate dynamics of informal support and its impact on patients' engagement in chronic care, this study used a mixed-methods approach and causal loop diagramming. By unravelling the complexity of informal support structures, this research aims to provide valuable insights that can inform the development of more effective and sustainable NCD care strategies in Tanzania, and potentially serve as a model for other LMICs facing similar challenges.

2. Methods

This study employed a mixed-methods approach to investigate the dynamics of informal support networks among patients living with NCDs in Tanzania. The research design integrated a personal network questionnaire for quantitative data collection and IDIs for gathering qualitative insights.

The study took place in the outpatient waiting rooms of one secondary and one tertiary healthcare facility: the Kiwanja Mpaka Health Centre and the Mbeya Regional Referral Hospital. These facilities were randomly chosen from the District Medical Officer's list of health facilities within the Mbeya City Council. Three experienced RAs proficient in both quantitative and qualitative methodologies were recruited from our institution and underwent thorough training on the use of the quantitative data collection tool and the semi-structured interview guide prior to data collection. Feedback from RAs and a pilot study involving 10 participants informed subsequent revisions to the questionnaire and interview guide, enhancing their clarity and relevance.

Over the course of ten days in August 2022, RAs approached all patients in the outpatient departments' waiting rooms to invite them to participate in the study. Eligible participants included all patients over the age of 18 who self-reported having been diagnosed with an NCD by a healthcare professional, so long as they did not display signs of cognitive impairment. RAs pre-screened potential participants by providing an introductory discussion and examples of NCDs. In order to avoid disrupting the work flow of the clinic and to preserve patients' position in the queue, consenting participants completed the questionnaire and interview after their consultation. The quantitative component of the study involved 108 patients with NCDs who participated in the personal network survey. For the qualitative portion, a sub-sample of 30 participants from the personal network survey were selected for semi-structured IDIs, according to the order in which they arrived at the clinic. Due to the small overall sample size and the anticipation that some participants would refuse to participate in IDIs after taking the time to complete the questionnaire, we were unable to randomly sample

participants for fear that we may not recruit sufficient IDI participants before completing recruitment for the quantitative questionnaire. These IDIs were audio-recorded and transcribed verbatim, serving as the primary data sources for constructing CLDs.

The quantitative questionnaire gathered information on patients' NCD(s), healthcare utilisation, and the informal social support received from members of their social network. We also asked participants for their consent to measure their blood pressure using clinically validated Omron blood pressure monitors. According to the WHO's blood pressure screening guidelines, we spaced measurements at three different time points throughout the questionnaire and reported blood pressure data as the mean of the final two measurements. Data collection was conducted in Kiswahili using tablets and the open-access ODK software (Hartung et al., 2010), with completed questionnaires securely uploaded to a server hosted at the authors' institute in Dar es Salaam, Tanzania. Access to this data was restricted to the institute's data manager and the authors of this manuscript. The quantitative questionnaire is described in more detail in Box S1 of the Supplementary File #1 (Bigna and Noubiap, 2019), and the ODK questionnaire XLS form is appended in supplementary file #2.

RAs conducted IDIs in Kiswahili using a semi-structured interview guide that provided research assistants with seven main questions to guide enquiry about what participants do to manage their chronic illness, what kind of support they receive in managing their illness, and the challenges they experience in managing their illness. There were further 'probing questions' within each general question designed to prompt the participant to provide more detail on their day-to-day experience of living with an NCD and accessing healthcare services, and to elaborate on the types and functions of informal support they receive for overcoming these struggles. We decided to design this work as a mixed methods study because we felt that a quantitative survey alone could not capture and adequately study such varied, complex social phenomena as informal support relationships. The semi-structured IDI guide is available in Supplementary File #3.

2.1. Analysis

Descriptive quantitative analyses explored participants' demographic and health characteristics, described the composition of their social networks and measured their receipt of non-material and material support. We additionally used social network diagrams to visualise the support networks of people living with NCDs, which allowed one to visualise an aggregated composition of patients' social networks and their receipt of social support across multiple sub-groups.

We proxied engagement in care by asking if patients' last NCD care visit was one month prior to today's visit, if they obtained medicines at their last NCD care visit, and if they had taken their prescribed NCD medications within the past week. If a participant visited a health facility one month ago and today is visiting the facility again, we could assume that they regularly renew their prescriptions, which providers typically only dispense as a one-month supply. We also considered the use of prescribed medications within the past week as a positive indication of engagement in care, while still allowing the inclusion of participants who may not take their medication every day, due in particular to the prevalent practice of drug rationing to cope with stockouts (Gyasi and Phillips, 2020; Adinan et al., 2019).

A recent study conducted in Tanzania indicates that the strongest predictor of receiving social support is having challenges with completing work or activities of daily living (Hooley et al., 2022), so we sought to investigate the intermediate steps of this process, hypothesizing causal loops between material support, engagement in care and economic or household productivity. We measured the relationship between each of these steps and investigated whether receiving material support at least monthly is associated with higher odds of being engaged in care and whether patients engaged in care have lower odds of missing workdays due to their NCD.

We analysed the text of the IDI transcripts to identify themes and extract quotations on the general challenges posed by living with NCDs using a phenomenological approach that sought to study patients' lived experiences and interaction with their social environment. We sought to identify and explore the specific challenges associated with remaining engaged in care and the role that both formal and informal forms of social protection play in helping patients to overcome these challenges. First, we deductively coded all discourse that referred to either somatic health, psychosocial well-being, social support, or challenges with completing work or activities of daily living. We then inductively coded each excerpt as specifically as possible, such that each code described a single, causal relationship (See Supplementary File #4 for complete list of codes).

We used these codes to construct an individual CLD for each IDI participant, retaining only codes occurring more than twice in order to simplify the interpretability of the resulting CLD. Each participant's CLD provided a visual representation of the self-reported causal relationships that exist between their utilisation of healthcare, physical health, psychosocial well-being, informal social support, and own economic or labour productivity. We then ordered CLDs by decreasing complexity, designating the most complex CLD as the 'anchor' CLD into which we

incorporated additional elements found in the remaining CLDs until we had constructed a master CLD that included all elements mentioned by all participants (Cassidy et al., 2021).

We used StataIC 16 for quantitative analysis (StataCorp, 2019), Dedoose for qualitative analysis (SocioCultural Research Consultants LLC, 2022), Python 3.9.7 and the 'NetworkX' package for network visualisation (Hagberg et al., 2008), and Vensim for constructing CLDs (<https://vensim.com/>).

2.2. Ethical review

This study was reviewed and approved by the appropriate institutional review board and national health research ethics committee, and all participants provided their written, informed consent. Approval reference numbers currently retained to maintain double-blind review.

3. Results

We begin by presenting the results of the quantitative questionnaire, first describing participants' characteristics, before describing and participants' informal care networks and receipt of social support. We then

Table 1
Summary characteristics of participants, disaggregated by gender (N = 108).

		Overall	Women	Men	P-Value
n		108	78	30	
Age, mean (SD)		60.2 (10.5)	59.4 (10.9)	62.4 (9.5)	0.164
Marital Status, n (%)	Living with partner	3 (2.8)	1 (1.3)	2 (6.7)	0.001
	Married	59 (54.6)	35 (44.9)	24 (80.0)	
	Separated	5 (4.6)	4 (5.1)	1 (3.3)	
	Widowed	41 (38.0)	38 (48.7)	3 (10.0)	
Education, n (%)	None	10 (9.3)	10 (12.8)		0.035
	Some primary	10 (9.3)	7 (9.0)	3 (10.0)	
	Primary	59 (54.6)	46 (59.0)	13 (43.3)	
	Some secondary	5 (4.6)	2 (2.6)	3 (10.0)	
	Secondary	19 (17.6)	11 (14.1)	8 (26.7)	
	College	5 (4.6)	2 (2.6)	3 (10.0)	
Household size, mean (SD)		4.1 (1.7)	3.9 (1.5)	4.7 (2.2)	0.105
Occupation, n (%)	Caring for home/children	12 (11.3)	12 (15.6)		0.002
	Public Servant	9 (8.5)	5 (6.5)	4 (13.8)	
	Retired	8 (7.5)	6 (7.8)	2 (6.9)	
	Self-employed, small business	26 (24.5)	24 (31.2)	2 (6.9)	
	Subsistence Farmer	49 (46.2)	30 (39.0)	19 (65.5)	
	Private Formal Sector	2 (1.9)		2 (6.9)	
Productivity loss due to illness, n (%)	Never	43 (39.8)	28 (35.9)	15 (50.0)	0.350
	Sometimes	58 (53.7)	44 (56.4)	14 (46.7)	
	Completely	7 (6.5)	6 (7.7)	1 (3.3)	
Days of work/productivity lost to illness, mean (SD)		8.5 (8.2)	8.7 (8.5)	7.8 (7.2)	0.696
Current HI, n (%)	Yes	95 (88.0)	68 (87.2)	27 (90.0)	1.000
Paid for own HI, n (%)	Yes	41 (43.2)	26 (38.2)	15 (55.6)	0.191
Current fee exemption, n (%)	Yes	12 (11.1)	10 (12.8)	2 (6.7)	0.504
Diabetes, n (%)	Yes	23 (21.3)	16 (20.5)	7 (23.3)	0.748
Hypertension, n (%)	Yes	85 (78.7)	63 (80.8)	22 (73.3)	0.398
Controlled Hypertension, n (%)	Yes	22 (25.88)	17 (27.0)	5 (22.7)	0.695
Epilepsy, n (%)	Yes	2 (1.9)	2 (2.6)		0.376
Asthma, n (%)	Yes	4 (3.7)	1 (1.3)	3 (10.0)	0.032
HIV, n (%)	Yes	17 (15.7)	12 (15.4)	5 (16.7)	0.870
Ulcers, n (%)	Yes	8 (7.4)	7 (9.0)	1 (3.3)	0.316
Other chronic illness, n (%)	Yes	9 (8.3)	5 (6.4)	4 (13.3)	0.244
Time since disease onset, n (%)	Less than 1 year ago	13 (12.0)	8 (10.3)	5 (16.7)	0.070
	Between 1 and 5 years ago	60 (55.6)	41 (52.6)	19 (63.3)	
	Between 5 and 10 years ago	29 (26.9)	26 (33.3)	3 (10.0)	
	More than 10 years ago	6 (5.6)	3 (3.8)	3 (10.0)	
Perceived health status, n (%)	Bad	3 (2.8)	2 (2.6)	1 (3.3)	0.973
	Moderate	55 (50.9)	40 (51.3)	15 (50.0)	
	Good	50 (46.3)	36 (46.2)	14 (46.7)	
Systolic BP, mean (SD)		143.1 (15.9)	144.1 (15.8)	140.6 (16.1)	0.316
Diastolic BP, mean (SD)		89.7 (11.6)	90.1 (11.6)	88.8 (11.8)	0.622
Stage II Hypertension, n (%)	Yes	71 (65.7)	52 (66.7)	19 (63.3)	0.920
Proportion of women in support network, mean (SD)		0.4 (0.4)	0.4 (0.4)	0.5 (0.4)	0.657
% of alters who provide emotional support, mean (SD)		0.8 (0.3)	0.8 (0.3)	0.7 (0.3)	0.225
% of alters who provide informational support, mean (SD)		0.7 (0.4)	0.8 (0.4)	0.7 (0.4)	0.589
% of alters who provide material support, mean (SD)		0.5 (0.4)	0.6 (0.4)	0.4 (0.5)	0.203

further contextualise these findings by presenting key quotes that demonstrate the themes identified during in-depth interviews, deepening our understanding of the relationship between informal support and engagement in care by visualising qualitative data using causal loop diagrams.

3.1. Participant characteristics

Our sample of 108 participants had a mean age of 60.2 years, 57 % were married or living with a partner while the rest were either widowed or did not have a partner, with 49 % of women and 10 % of men being widowed (Table 1). Over 80 % of participants had at least a primary education while subsistence farming (46.2 %) and being self-

Table 2
Summary characteristics of participants' social ties, disaggregated by gender of social ties (N=208).

		Overall	Women	Men	P-value
n		208	94	114	
Relationship to participant, n (%)	A child	113 (54.3)	51 (54.3)	62 (54.4)	0.093
	Husband/Wife/Partner	46 (22.1)	15 (16.0)	31 (27.2)	
	Other family member	37 (17.8)	19 (20.2)	18 (15.8)	
	Other	12 (5.8)	9 (9.5)	3 (2.6)	
Homophily on gender, n (%)	No	116 (55.8)	29 (30.9)	87 (76.3)	<0.001
	Yes	92 (44.2)	65 (69.1)	27 (23.7)	
Age, n (%)	Less than 20 years old	3 (1.4)	2 (2.1)	1 (0.9)	0.153
	20–30 years old	30 (14.4)	17 (18.1)	13 (11.4)	
	30–40 years old	68 (32.7)	29 (30.9)	39 (34.2)	
	40–50 years old	46 (22.1)	23 (24.5)	23 (20.2)	
	50–60 years old	35 (16.8)	17 (18.1)	18 (15.8)	
	More than 60 years old	26 (12.5)	6 (6.4)	20 (17.5)	
Homophily on age, n (%)	No	174 (83.7)	81 (86.2)	93 (81.6)	0.482
	Yes	34 (16.3)	13 (13.8)	21 (18.4)	
Time known, n (%)	1–5 years	46 (22.1)	20 (21.3)	26 (22.8)	0.929
	5–10 years	21 (10.1)	9 (9.6)	12 (10.5)	
	More than 10 years	141 (67.8)	65 (69.1)	76 (66.7)	
Residential proximity, n (%)	In the same household	89 (42.8)	41 (43.6)	48 (42.1)	0.948
	In the same village/town	32 (15.4)	15 (16.0)	17 (14.9)	
	In the same district	29 (13.9)	11 (11.7)	18 (15.8)	
	In another district in Mbeya Region	13 (6.2)	6 (6.4)	7 (6.1)	
	In another region	45 (21.6)	21 (22.3)	24 (21.1)	
Frequency of contact, n (%)	Every day	153 (73.6)	78 (83.0)	75 (65.8)	0.034
	A few times a week	40 (19.2)	14 (14.9)	26 (22.8)	
	Once a week	10 (4.8)	2 (2.1)	8 (7.0)	
	A few times a month	1 (0.5)	1 (0.9)	1 (0.9)	
	Once a month	4 (1.9)	4 (3.5)	4 (3.5)	
Provides emotional support?, n (%)	No	54 (26.0)	22 (23.4)	32 (28.1)	0.545
	Yes	154 (74.0)	72 (76.6)	82 (71.9)	
Frequency of emotional support, n (%)	Every day	0	0	0	0.990
	A few times a week	3 (1.9)	1 (1.4)	2 (2.4)	
	Once a week	11 (7.1)	5 (6.9)	6 (7.3)	
	A few times a month	11 (7.1)	5 (6.9)	6 (7.3)	
	Once a month	69 (44.8)	32 (44.4)	37 (45.1)	
	Less than once a month	60 (39.0)	29 (40.3)	31 (37.8)	
Provides informational support?, n (%)	No	70 (33.7)	31 (33.0)	39 (34.2)	0.968
	Yes	138 (66.3)	63 (67.0)	75 (65.8)	
Frequency of informational support, n (%)	Every day	0	0	0	0.039
	A few times a week	0	0	0	
	Once a week	14 (10.1)	2 (3.2)	12 (16.0)	
	A few times a month	13 (9.4)	4 (6.3)	9 (12.0)	
	Once a month	76 (55.1)	38 (60.3)	38 (50.7)	
	Less than once a month	35 (25.4)	19 (30.2)	16 (21.3)	
Provides material support?, n (%)	No	94 (45.2)	47 (50.0)	47 (41.2)	0.261
	Yes	114 (54.8)	47 (50.0)	67 (58.8)	
Frequency of material support, n (%)	Every day	3 (2.6)	3 (6.4)	0	0.012
	A few times a week	29 (25.4)	8 (17.0)	21 (31.3)	
	Once a week	26 (22.8)	10 (21.3)	16 (23.9)	
	A few times a month	5 (4.4)	0	5 (7.5)	
	Once a month	24 (21.1)	15 (31.9)	9 (13.4)	
	Less than once a month	27 (23.7)	11 (23.4)	16 (23.9)	
Type of material support: money, n (%)	No	19 (16.7)	13 (27.7)	6 (9.0)	0.017
	Yes	95 (83.3)	34 (72.3)	61 (91.0)	
Type of material support: transport, n (%)	No	62 (54.4)	28 (59.6)	34 (50.7)	0.459
	Yes	52 (45.6)	19 (40.4)	33 (49.3)	
Type of material support: other, n (%)	No	85 (74.6)	31 (66.0)	54 (80.6)	0.122
	Yes	29 (25.4)	16 (34.0)	13 (19.4)	
Amount of support provided (USD), mean (SD)		19.9 (23.9)	13.8 (13.0)	23.1 (27.5)	0.033
Purpose of money: clinic/pharmacy fees, n (%)	No	93 (79.5)	43 (89.6)	50 (72.5)	0.043
	Yes	24 (20.5)	5 (10.4)	19 (27.5)	
Purpose of money: transport fare, n (%)	No	31 (24.4)	15 (27.8)	16 (21.9)	0.582
	Yes	96 (75.6)	39 (72.2)	57 (78.1)	
Purpose of money: other, n (%)	No	67 (54.0)	28 (52.8)	39 (54.9)	0.960
	Yes	57 (46.0)	25 (47.2)	32 (45.1)	

employed in a small business (24.5 %) were the most commonly reported occupations.

Hypertension and diabetes were the most commonly reported NCDs, affecting 79 % and 21 % of participants respectively, with our own blood pressure measurements indicating that 26 % of those previously diagnosed with hypertension had apparently achieved control of their blood pressure. Our measurements also indicated that 65 % of participants had stage II hypertension, 7 % of which had not previously been diagnosed with hypertension. Most participants reported having begun treatment for their NCD within the last five years (67 %), with 27 % having been diagnosed between five and 10 years prior to the interview and 5 % having been diagnosed more than 10 years prior to the interview.

Our research found that an overwhelming 94 % of participants actively sought care for their chronic condition in the past month, with almost all of these people receiving prescribed medication during their healthcare visits. In addition, 81 % of participants reported adhering to their medication regimen over the past week. These compelling results underscore the high level of engagement in care among people living with chronic conditions in the urban setting of Mbeya, exceeding our initial expectations.

However, this commitment to engagement in care resulted in a remarkably homogeneous sample, limiting our ability to detect significant associations between social support, engagement in care and NCD-related absenteeism. The overwhelming consistency in participants' care-seeking behaviour presented a challenge in identifying meaningful variation for statistical analysis. Detailed results of these analyses, including any trends or patterns observed, are presented in Table S.1 in the Supplementary File #1.

In terms of formal social health protection, all but 2 participants had either health insurance or a user fee exemption. However, participants frequently indicated that access to health insurance coverage was facilitated by their social network, in that only 41 % paid for their own health insurance membership and only 24 % were the principle beneficiary, with most participants being insured under one of their children's policies (Table 1).

3.2. Personal networks and informal support

Participants described a total of 208 social ties, for a mean of 1.93 social ties each (SD: 0.79). Participants' children (54 %) were the most common type of relation, followed by one's spouse or partner (22 %), other family members (18 %), and 'other' relation types (6 %). Ties were most likely to provide emotional and informational support, with 74 % and 66 % of social ties providing these forms of support, respectively (Table 2). While only 55 % of ties provided material support, those providing material support did so more frequently than those providing emotional support or informational support, as 51 % provided material support at least weekly while only 9 % and 10 % did so for emotional and informational support, respectively.

Those who provided material support to patients mostly did so by directly giving them money (83 %) while nearly half of social ties provided transport and a quarter provided 'other' support, namely giving participants food or other goods. Transport to the health facility and elsewhere were the most common intended uses for financial support (76 %), followed by 'other' purposes such as the purchase of food or other goods (46 %) and lastly for direct medical costs (21 %).

Men and women receive similar amounts of support overall (Fig. 1), although men receive substantially more contributions from 'other' ties than women do. However, as 'other' ties infrequently occur in this sample's social networks, their support is insufficient to yield any detectable gender-based differences in the receipt of informal support.

We did detect a small difference in the amount of material support received by those with and without NCD-related productivity limitations (Table 3). While similar proportions of partners and other family members provide material support, they provide more frequent support to patients with productivity limitations than to those without (Fig. 1).

3.3. Patients' struggles and support received

The IDIs elicited rich discourse regarding the daily challenges and concerns faced by patients living with a NCD, as well as the role of social support in helping them overcome these struggles and alleviate their worries. Participants mentioned 36 causal factors and 27 effects associated with their physical health, psychosocial well-being, social support, or productivity. The most frequently mentioned causal factors were 'Symptoms', 'Financial struggles', 'Social participation', 'Having children', and 'Fatigue'. Meanwhile, the most frequently mentioned effects or outcomes were 'Psychosocial wellbeing', 'Adherence', 'Stress', 'Financial struggles' and 'Symptoms'. These causal factors and effects formed 79 cause-effect relationships, and we present the most frequently mentioned ones in Table 4.

'Financial struggles' and 'symptoms' are particularly noteworthy, as they feature among both the most frequently mentioned causal factors and effects, with Fig. 2 demonstrating their interdependence via a complex web of balancing and reinforcing loops that mediate their relationship. 'Adherence' and 'stress' were major intermediate nodes between 'financial struggles' and 'symptoms'. For example, patients' adherence to NCD treatment was hindered by the occurrence of side-effects, but similarly promoted by the worsening of symptoms, demonstrating balancing processes in which patients report being more likely to adhere to treatment when faced with productivity-limiting symptoms and less likely to remain adherent if they experience similarly limiting side-effects.

Many participants reported a loss of productivity due to their illness, leading to financial difficulties that made it difficult for them to afford healthcare services. This, in turn, caused some participants to forgo treatment or experience stress, further exacerbating their illness and negatively affecting their psychosocial wellbeing (Table 4, Fig. 2). Despite these challenges, however, many patients were able to interrupt this cycle through informal financial and material support, emotional support, and formal social health protection. These forms of support played a critical role both in promoting psychosocial well-being and encouraging engagement in care.

Most participants reported that their chronic illness either sometimes (54 %) or completely (6 %) limits their capacity to work or perform household duties (Table 1). IDIs corroborated this finding, as participants frequently mentioned that their illness limits their ability to work their land, with important consequences regarding food security and their ability to follow physician-recommended dietary modifications.

When asked about the consequences of their illness, participants frequently cited experiencing fatigue and weakness as a result of having hypertension or diabetes, which limited their capacity for physical labour and self-sufficiency. Women also described how their need to reduce and modify their work reinforces traditional gender roles, reporting that on top of struggling with their own health and productivity as they age, they are expected to take on additional caregiving roles:

"I have to work because I am alone, as a woman I have to do things like bending over, cooking! I used to farm but now I have stopped. I have actually reduced agriculture, I think that's all, but I do these small jobs like washing and others, normal domestic jobs of a woman." (KI #7)

Additionally, various issues related to economic productivity were highlighted, including financial struggles and lost productivity. These concerns were mentioned in 32 and 46 instances, respectively. To illustrate the impact of productivity loss, we have included an excerpt of a key loop in Fig. 3. This balancing loop demonstrates how financial support can alleviate the financial struggles caused by fatigue and productivity loss, ultimately improving patients' food security and adherence to physician-prescribed dietary modifications.

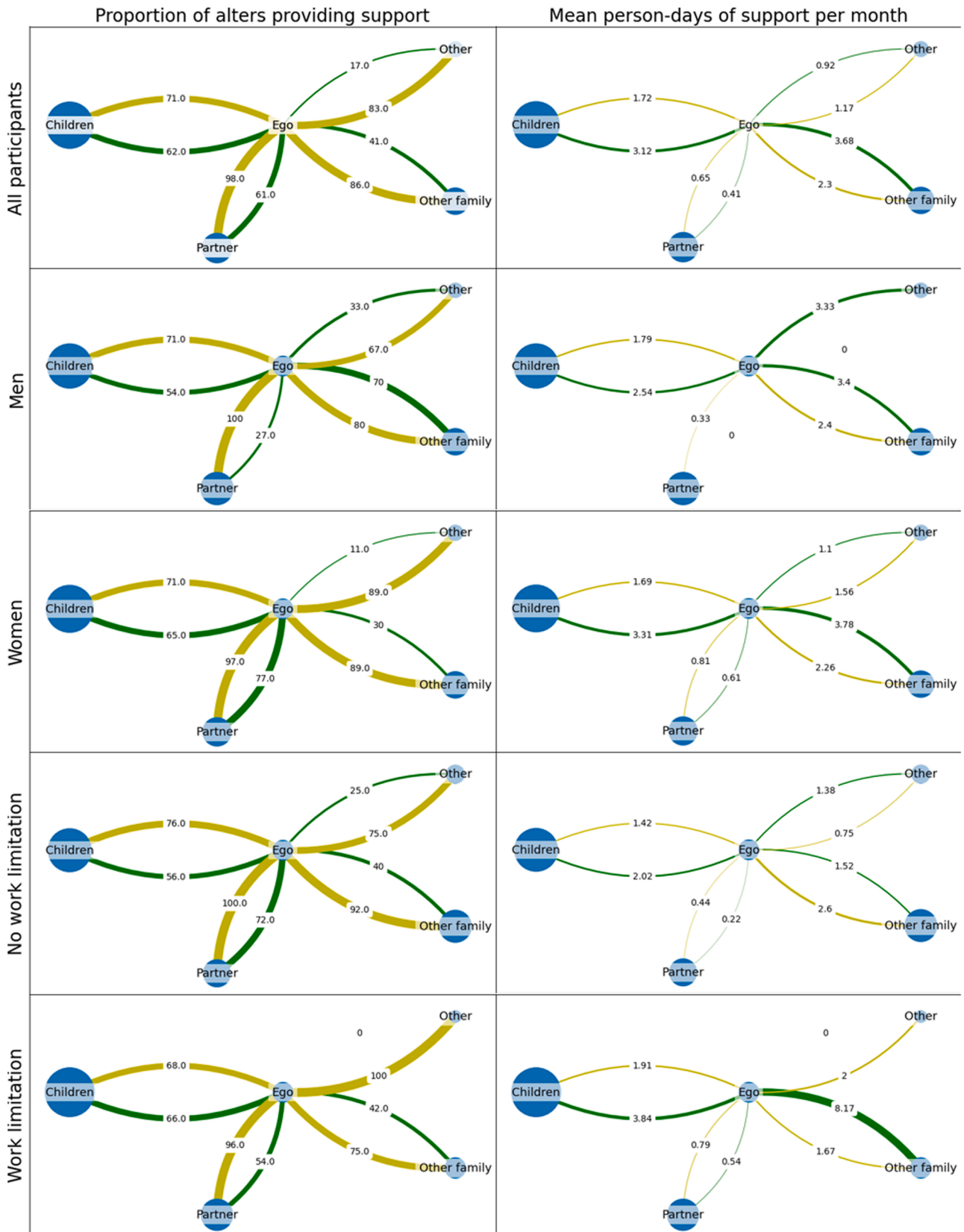


Fig. 1. Average cluster graphs depicting the amount of support received by participants from their alters. Alter node size represents the relative prevalence of each relation type within participants' personal support networks. The left column represents the proportion of alters that provide non-material support (blue) and material support (green). The right column represents the average number of support events provided by each type of alter per month.

Table 3

Unequal variance t-test for differences in the mean amount of informal support received between men and women, and between those with and without NCD-related work limitations (N = 108).

Group	Monthly non-material support events			Monthly material support events		
	Mean	Standard error	P-value	Mean	Standard error	P-value
Men (n = 30)	2.63	0.56	0.234	3.83	1.10	0.181
Women (n = 78)	3.12	0.38		5.17	0.95	
No NCD-related work limitations (N = 43)	3.33	0.57	0.208	3.35	0.79	0.041
NCD-related work limitations (n = 65)	2.77	0.36		5.75	1.11	

Table 4

Participants' 20 most frequently mentioned cause and effect relationships that affect their experience of NCD symptoms, engagement in care, psychosocial wellbeing, and social support.

Cause	Effect	Polarity	Count
Emotional support	Psychosocial wellbeing	+	20
Health insurance	Adherence	+	18
Children	Financial support	+	16
Children	Emotional support	+	15
Symptoms	Fatigue	+	11
Prayer	Psychosocial wellbeing	+	11
Fatigue	Productivity loss	+	10
Stress	Symptoms	+	10
Children	Health insurance	+	9
Social participation	Emotional support	+	8
Symptoms	Productivity loss	+	8
Productivity loss	Financial struggles	+	8
Dietary modifications	Symptoms	-	22
Adherence	Symptoms	-	19
Psychosocial wellbeing	Symptoms	-	10
Symptoms	Psychosocial wellbeing	-	8
Financial struggles	Psychosocial wellbeing	-	7
Stress	Psychosocial wellbeing	-	7
Health Insurance	Financial struggles	-	7
Dietary modifications	Psychosocial wellbeing	-	6

“About getting help, we should tell you that we are not lacking! And at least if it’s cash, they try to use it for us so that we don’t pack [our shopping bag] empty, then we buy fruits in large quantities and eat them, so they try to bring them to us, and they reduce such a problem.” (KI #7)

“[...] next time you will find that they have sent food, even this one [adult child] from Iringa, today we received the load they sent” (KI #21)

Participants’ frequently mentioned that their reduced physical capacity due to chronic illness increased their reliance on support from their social network. The reinforcing loop between receiving and providing financial support demonstrates its reciprocal nature (Fig. 3). Participants were cognizant of this reciprocity both in the transactional nature of performing favours in exchange for support and in the longer-term expectation of receiving support from younger people whom they had supported in the past:

“So I had to be charming with ordinary people. But the same people are the ones who give me a lot of support, you can’t believe it! It’s just your honesty and the way you treat those whom you see as little ones today.” (KI #20)

Although participants appreciated receiving support, many

expressed feelings of guilt and concerns about being a burden on their loved ones. This was especially true when they became less able to reciprocate support. One participant demonstrated this dynamic when they mentioned that they expected that securing their own livelihood would improve their relationships with peers:

“Then when you don’t have an income, maybe you’ll be going around struggling, asking if you can help with this and that [in exchange for money]. Then they start saying, ‘this one is bothering us!’”(KI #7)

“Because I can’t do various economic activities, I have been affected personally, because we can’t depend on children all the time and we have to have ways of earning our own income.” (KI #7)

The CLD indicates a reinforcing loop where participants’ unstable financial situation is reported to be a stressor that exacerbates their blood pressure, leading to reduced productivity. This feedback loop highlights the complex interplay between financial instability, health outcomes, and productivity (Fig. 3).

“It [blood pressure] is generated by income, thinking about what it will be like now, how I will live, and then there is also a child who was picked up and given to me and I live with him now [participant was given a child to care for]” (KI #13)

Despite facing limitations in productivity and labour due to chronic illness, participants reported actively engaging with savings groups and other microfinance groups at the community level. These groups allow participants to exercise financial autonomy and manage their financial needs. Although the small loans offered through microfinance groups were vital for financing travel to health facilities and covering other expenses, participants acknowledged the risk of becoming trapped in a cycle of debt and poverty if they were unable to repay their loans in a timely manner:

“And if you sell [crops] now, you can take the profit to the loans [...] you find that even the capital you have dies there and you have to pay people’s money, you have to go around and pay, and day by day you find you don’t even have a hundred left [100 Tanzanian shillings, approximately 0.05 USD]] and you have to borrow again [or] you go to borrow somewhere else.” (KI #13)

“Or if they send me money for food, I have already turned the corner and gone to pay the debts and then I am still left with the thought that even though I have paid the debt, how will I live now?” (KI #13)

Table 1 shows that while patients can expect only 50 % of their social ties to have provided them with material support over the past month (Tables 1), 50.1% do so at least weekly. This is in stark contrast to emotional support, where 80 % of the participants’ social ties provide emotional support, but only 9.1 % do so at least weekly. Patients often mentioned that their children were the ones most frequently providing support, and the survey indicated that they accounted for over half of all listed social ties. Parents often invest heavily in their children, with the expectation that their children will eventually provide for them in old age.

This includes supporting their children in migrating to larger towns and cities for economic opportunities, with the hope that their children will reciprocate this support in the future. However, one participant expressed her concern by saying, “the more one travels, the more one loses their way,” in reference to her children who had migrated to another city and failed to meet her expectations for reciprocal support.

Many patients cited that benefitting from their children’s health insurance coverage was one of the most valuable forms of support they receive. For example, although 88 % of patients reported being currently enrolled in a health insurance scheme, 57 % were beneficiaries of someone else’s policy. The role of health insurance in promoting engagement in care was mentioned by 18 separate participants, and the role of health insurance in avoiding financial struggles by nine

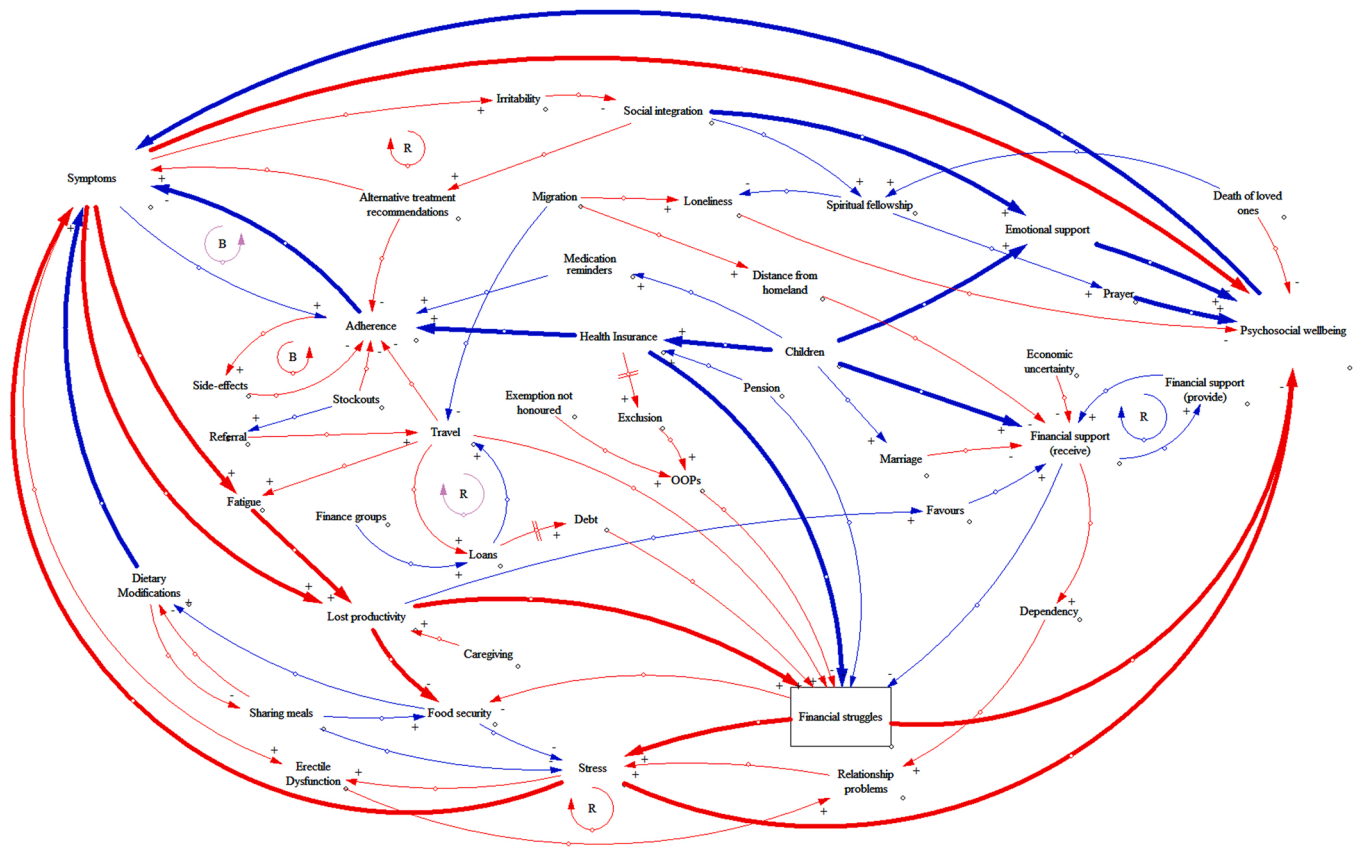


Fig. 2. Causal loop diagram of the causal relationship between chronic illness and psychosocial wellbeing, moderated primarily by one’s economic or homestead productivity and one’s receipt of social support. Blue arrows indicate qualitatively beneficial relationships and red arrows qualitatively negative relationships, bolded arrows indicate the 20 most frequently mentioned causal relationships (Table 4), and arrow polarity (+/-) indicates the quantitative direction of the relationship.

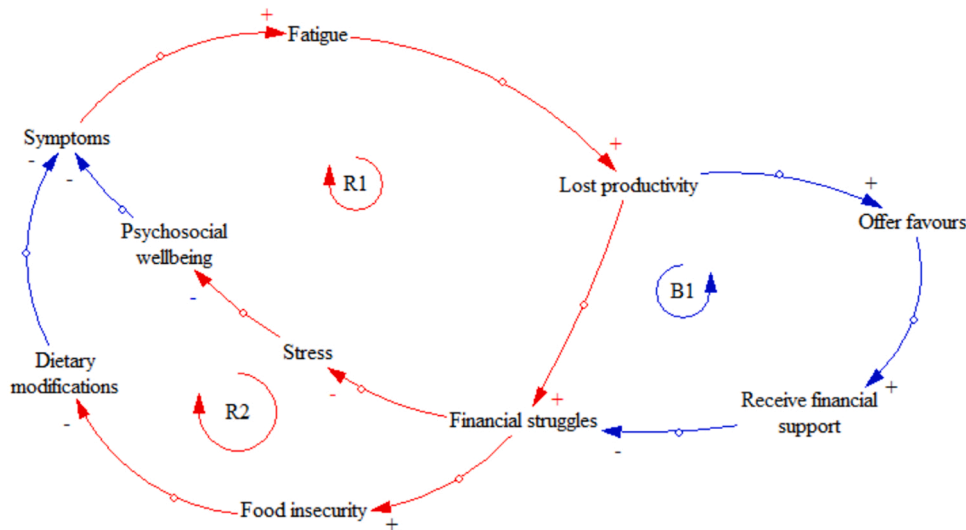


Fig. 3. Excerpt of causal loop diagram indicating the negative reinforcing effect of fatigue, productivity loss and financial struggles upon the management of psychosocial wellbeing and NCD symptom management (R1), and the balancing effect of offering favours and receiving financial support (B1). Note that B1 balances the negative effects of both R1 and R2.

participants, indicating that they appreciate the financial security associated with having health insurance, particularly given the chronic nature of their illnesses: “It has helped me a lot, you know illness can appear and you don’t have money, right now even if I get sick I just take my card and go to the hospital (KI #2).”

According to IDI participants, financial difficulties and traumatic life

events were triggers for the onset of illness, particularly for hypertension. These stressors were described as causing psychological challenges, which participants referred to using the phrases “*kuna na mawazo sana*” and “*kufikiria sana*” – meaning having many thoughts or thinking too much. As a consequence of this prolonged stress, participants reported developing hypertension, attributing it to the burden of

constantly dealing with stressful thoughts and emotions:

“As for me, I think that this blood pressure is the result of thinking too much. I have thought too much because of the life we went through (KI #25).”

Participants frequently observed that receiving emotional support can have a direct effect upon both hypertension control and the promotion of psychosocial well-being (Fig. 3):

“There is relief because if you consider the [blood] pressure, by receiving that support, even kind words alone can affect you. But now due to this social support and my family, I see that they are building me up because, you can have a lot of stressful thoughts but when you come home someone comforts you and the pressure is already decreasing.” (KI #6)

In addition, participants recognized the importance of social participation in their ability to cope with chronic illness. They reported seeking solidarity with their peers and spiritual support from their respective religious communities, which helped them navigate the challenges of living with a NCD. Social connections were seen as crucial sources of emotional support, providing participants with a sense of belonging and meaning in their lives:

“When you participate in a group of your peers, you do what your peers do, you don’t see yourself as different and psychologically you see yourself as the same.” (KI #10)

“It [church group] helps me when I have problems, when I’m sick they come to see me, pray for me.” (KI #17)

This discourse helped shed light on the intricate interplay between social connectedness, physical health, and psychosocial wellbeing. Fig. 4 illustrates how poor physical health can negatively impact social participation, underscoring the crucial role of social connections in promoting psychosocial wellbeing through emotional support and prayer. However, it is worth noting that participants in the study also described the inverse relationship, explaining how poor psychosocial wellbeing directly and negatively affected their hypertension symptoms.

It also is noteworthy that not all forms of social integration and ‘support’ were helpful to participants. While members of their social network readily provided informational support to participants, not all was well-informed, leading to misguided advice regarding the management of their NCD. Although this was not a prevalent issue, the harmful consequences of misinformation and ill-informed advice were evident in one patient’s decision to stop taking prescribed medicines in favour of traditional remedies:

“They said that it is better to stop taking these drugs, they can cause a bigger problem. If you leave them, the blood pressure will settle down on its own. [...] I was asked by the doctor “why haven’t you finished your medicine? Give me an explanation!” [...] In fact, when he tested me, it [BP] seemed to have gotten higher and he advised me that: ‘we are the healers, we need to be listened to, we have studied these things, these things on the street are not good, many people fall by the wayside and then they accuse witches and then rely on traditional medicines instead of experts so that they can advise them on which methods they should use.’ (KI #9)

4. Discussion

This study found that patients seeking care for NCDs in Tanzania face a number of barriers that hinder the management of their disease. However, patients received substantial support from their social network that allowed them to cope with and overcome these barriers. Participants frequently complained that their NCD causes them to feel weak and fatigued, and 60 % face difficulties in completing their work or household duties, which hinder their ability to pay for necessary healthcare, food, and household goods. Despite being an urban sample, subsistence farming was the most frequently reported occupation, making their economic productivity particularly sensitive to illness-related fatigue and weakness. Patients’ resulting financial struggles created demand for financial support, which was most frequently provided by one’s children.

The financial and material support from social ties helps participants to cope with both the direct and indirect costs of their illness and engagement in care (Dhankhar et al., 2021; Gulamhussein et al., 2023). Despite most participants being registered with health insurance, they often received financial support for direct medical costs of care. This may be related to inefficiencies in the health system, and/or frequent medicine stockouts in lower-level and public facilities, leading patients to purchase them in private pharmacies not included in health insurance benefit packages. Some participants reported borrowing money from loved ones in order to avoid impoverishing catastrophic health expenditure, while others incurred self-described catastrophic health expenditure that was compensated by their social networks through the provision of food and other forms of material support. Borrowing money from friends and family members is a frequently used coping strategy in LMICs to cope with the costs of illness, and recent studies have described the prevalence of such strategies to fund household health expenditure (Dhankhar et al., 2021; Gulamhussein et al., 2023). While there is limited evidence on the prevalence of distress financing for NCD care in Tanzania, one study found that over 85 % of those seeking care for injuries experienced catastrophic health expenditure, despite many

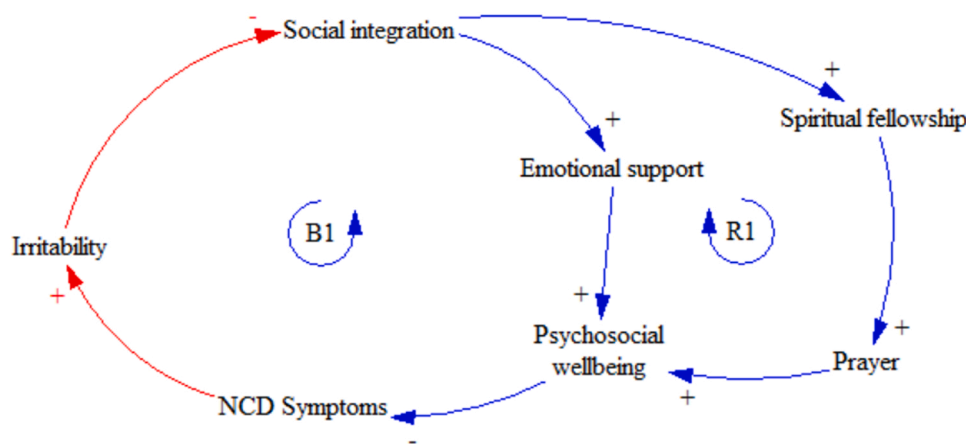


Fig. 4. Excerpt of causal loop diagram indicating the balancing emotional support and prayer loops that moderate symptoms’ negative effect on mood and social integration.

receiving social support and/or selling their possessions or property (Gulamhussein et al., 2023). This indicates that while patients can expect social networks to assist them in financially coping with their illness, remaining engaged in NCD care can still represent a major cost to both patients and providers of informal support. This phenomenon deserves further study from the perspective of informal caregivers, who may themselves resort to distress financing when caring for their sick or aging loved ones (Mohd Hassan et al., 2022).

Some patients report avoiding seeking healthcare until the opportunity cost of being ill outweighs the direct medical and non-medical costs of NCD care. This finding is in line with previous studies, which estimated that the opportunity cost of illness-induced absenteeism in LMICs can grow to exceed direct medical costs, while weak social security systems can make LMIC patients' absolute illness-induced opportunity costs even higher than those in high-income countries (de Francisco et al., 2015). While unable to perform regression analyses, this study found that participants with illness-related absenteeism receive more social support than those who do not, consistent with previous findings in both rural and urban Ghana, and rural Tanzania (Bigna and Noubiap, 2019; Mwangome et al., 2017). However, patients included in this study listed fewer informal support providers and received less support than those of a study in rural Tanzania, receiving seven fewer days of non-material support per month and 1.8 fewer days of material support per month (Hooley et al., 2022).

Due to the poor availability of NCD care in rural Tanzania (Adinan et al., 2019; Peck et al., 2014), participants reported that they sought to mitigate their direct non-medical health expenditure and NCD-related opportunity costs by migrating from the countryside to Mbeya. However, rural-urban migration may also be partially responsible for the substantial difference between the amounts of non-material support received by urban Mbeya residents and rural Ifakara residents. Despite continuing to receive similar levels of material support, we suspect that living in an urban area rather than a rural one imposes a social cost on patients when geographic distance and dispersion of supportive ties erode the quality and quantity of emotional support (Bilecen and Vacca, 2021).

While differences in the structure of urban and rural social networks remain understudied in Tanzania, studies in other contexts similarly report that first-generation migrants receive less social support than locals, and have more fragmented social support networks (Bilecen and Vacca, 2021; Vacca et al., 2018). Improving the accessibility of NCD care in primary and secondary health facilities could reduce patients' direct and indirect costs of NCD care and eliminate the need to migrate closer to a hospital. Doing so could also preserve the more supportive kin and peer social structures that are evident in rural Tanzania, but these findings also highlight the need to not forget the urban elderly, who may be more likely to experience social isolation and loneliness than their rural peers (Kasiram and Hölscher, 2015; Tomita et al., 2021).

While we know that remittances and material support are important resources for the elderly in SSA (Hooley et al., 2022; Burns et al., 2005; Danso-Wiredu and Poku, 2020; Harling et al., 2020a), there is limited evidence of the role of social cohesion and emotional support as determinants of healthy aging in the SSA context. Past work from other contexts thoroughly documented the role of non-material social support in promoting physical health and psychosocial wellbeing (Burns et al., 2005; Sorkin et al., 2002; Reblin and Uchino, 2008; Hoogendijk et al., 2016). For example, the LASA has studied aging adults since 1992 and found that aging adults with larger and more diverse support networks have lower all-cause mortality (Hoogendijk et al., 2016; Ellwardt et al., 2015). A recent study from South Africa produced similar findings demonstrating that older adults with larger and more diverse support networks are less likely to experience cognitive impairment (Harling et al., 2020b), while a Tanzanian study of stroke survivors has found that higher social connectivity protects against the development of symptoms of depression (Saadi et al., 2018). Future work should aim to better understand the importance of emotional and informational support in

both protecting against the development of NCDs and promoting engagement in NCD care in SSA. Such data will assist in the design of interventions that could promote the social participations of aging Tanzanians, with the aim of reducing their burden of disease and better equipping them to manage their illness in a supportive social environment.

In line with the high prevalence of patients' children in their support networks, the majority of the support received by patients came from their children. However, individual family members other than children provided more support on average than individual children. While work in other SSA contexts has indicated that women provide more informal care and support than men (Bhan et al., 2020; Nortey et al., 2017), this study and our previous work in rural Tanzania found that men are more likely to be named as supportive social ties than women (Hooley et al., 2022). This study also found that men provide more frequent informational and material support than women, however, expectations around women's traditional gender role as caregivers may have biased recall towards underreporting women's contributions or taking them for granted (Agyemang-Duah et al., 2019). Other studies found that Tanzanian women's role as caregivers may become particularly burdensome as they age, reporting that "[they] never graduate from caregiving roles", as they continue to be expected to care for their grandchildren (Rutagumirwa et al., 2020).

While caring for grandchildren may demonstrate reciprocity if older women continue to receive support from their children, our study's participants reported that doing so is fatiguing and negatively impacts their own health and productivity. While we did not study the burden of providing informal care, other work indicates that social ties who provide care to the elderly or those living with NCDs may experience burnout or compassion fatigue (Gérain and Zech, 2021). Previous work has studied the emotional burden of caring for sick or aging loved ones (Alves et al., 2019; Converso et al., 2020), however future studies could shed light on how best to reform social security to better alleviate caregivers' financial burden of providing informal care to sick or aging family members in LMICs.

This study also has some limitations to take into consideration. Firstly, this sample of well-engaged NCD patients may not be representative of those who do not have access to healthcare services. Secondly, the small geographic area of the study potentially limits the generalizability of our findings, while a lack of data on socioeconomic status made it difficult to quantify the receipt of financial support relative to participants' own financial means. Lastly, this study lacks information on the actual amounts of money spent on healthcare and social care, which may be important to fully understand the financial burden faced by patients and their support networks.

4.1. Conclusions

This study provides novel and interesting insights on the relevance of personal social networks in supporting patients coping with NCDs, and in complementing and filling gaps in the formal social and health protection systems in Tanzania and in similar settings. This mixed methods study sheds light on the complex interplay between psychosocial factors, social support, and NCD management. The use of both quantitative and qualitative methods allowed for a more comprehensive understanding of the complex ways in which patients experience and navigate engagement in care, which can inform the development of more effective interventions and policies.

CRedit authorship contribution statement

Brady Hooley: Writing – review & editing, Writing – original draft, Visualization, Methodology, Investigation, Formal analysis, Conceptualization. **Grace Mhalu:** Writing – review & editing, Methodology, Data curation. **Sally Mtenga:** Writing – review & editing, Supervision, Project administration, Methodology, Data curation. **Fabrizio Tediosi:**

Writing – review & editing, Supervision, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ssmhs.2024.100029.

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