Surviving the Epidemic: Families and Well-Being, Malaw
1998–2013

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Abstract
Across Eastern and Southern Africa (ESA), a remarkable cohort is reaching middle and older ages: those who have survived the AIDS epidemic. Nobody could escape an epidemic that was devastating for both its health and social implications. Were the survivors of this cohort just lucky? Or did they systematically differ in critical characteristics? What promoted survival and resilience in such a terrible context, and what influenced well-being among the survivors and their families? And for all of these questions, did the epidemic cause persistent divergences in families’ well-being because misery reinforced itself? These and related questions about “Surviving the Epidemic” (STE) are being studied by exploiting an unusually rich data source: the Malawi Longitudinal Study of Families and Health (MLSFH) cohort, 1998–2013.

1 Introduction
Across Eastern and Southern Africa (ESA), a remarkable cohort is reaching middle and older ages: those who have survived the AIDS epidemic. Some were infected with HIV, but everybody in this cohort was affected by HIV. Nobody could escape an epidemic that was devastating for both its health and social implications. Members of this cohort have weathered—some better, some worse—what is arguably the greatest global health crisis of the late 20th and early 21st century, one that struck hard in a region also dealing with poverty, famines, and basic uncertainties of life. As they grew older, members of this cohort saw some of their children, spouses and friends suffer and then die. Were the survivors of this cohort just lucky? Or did they systematically differ in critical characteristics? What promoted survival and resilience in such a terrible context, and what influenced well-being among the survivors and their families? Surely, whether one became HIV+ or not, and whether one had access to, and took advantage of, biomedical treatment. But survival and well-being also depended on other factors, such as social networks, family structures, life-course transitions, husband-wife interactions, perceptions of health and mortality risks, decisions to migrate, environmental influences, access to information and health care, etc. How did these factors influence life and death, and how did they affect survivors’ well-being, health and happiness? How did the children of survivors fare, and how did orphans? And for all of these

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questions, did the epidemic cause persistent divergences in families’ well-being because misery reinforced itself? Or, were there patterns of recovery and resilience, and what predicts these patterns? Even if we are approaching an “End of AIDS” as a result of biomedical progress (Deeks et al. 2013; Havlir and Beyrer 2012; The Economist 2011), how will the imprints of the epidemic on well-being, health, social and human capital shape societies in ESA in the years to come?

All these questions are centered around the theme of *Surviving the Epidemic* (STE). To address these issues, this paper exploits an unusually rich data source: the Malawi Longitudinal Study of Families and Health (MLSFH) cohort, 1998–2013. The MLSFH cohort experienced the beginning of the epidemic, when they began to see their relatives die, and the diminution of the crisis, when incidence declined, rapid-results testing was developed, and life-saving and life-prolonging therapies became available. The MLSFH 1998–2013 provides a lens on the lives of the remarkable ESA cohort who survived the epidemic’s rise, peak and decline across a 15-year time period, including data on mortality, well-being, sexual behaviors, marriage, family structures, migration, social networks and transfers.

2 Understanding what mattered for surviving the epidemic

2.1 Individual characteristics, perceptions and life events

Selected key aspects related to surviving the epidemic include:

**Gender, schooling and wealth:** They are among the most commonly studied characteristics influencing HIV infection, and thus surviving the epidemic, but in many cases, results defy common assumptions. For example, although research and programs have focused primarily on young women’s HIV risk, men are less likely to be tested and initiate ART, and are more likely to die of AIDS, even though women are more likely to be infected (Dovel et al. 2015; Harrison et al. 2015; UNAIDS 2013; Venkatesh et al. 2011). Wealth is closely associated with HIV status, but contrary to previous expectations, HIV infection is often highest among the wealthiest in ESA, possibly as a result of partnership practices (Mishra et al. 2007; Poulin et al. 2015; Swidler and Watkins 2007). Yet, what we know about relationships between HIV infection and wealth is limited, as analyses mostly rely on cross-sectional data for what is a dynamic health–wealth relationship (Chin 2010).

Similarly, a positive relationship between schooling and HIV prevalence has often been found in ESA (Fortson 2008; Hargreaves et al. 2013), but it’s possible that this relationship could change over time due to the well-educated being more able to adapt (Gregson et al. 2001; Hargreaves et al. 2015)—a hypothesis that has seldom been tested, in part due lack of longitudinal data.

**HIV testing and risk perceptions:** HIV testing was once touted as a strategy for HIV prevention (Fonner et al. 2012; Holbrooke and Furman 2004; WHO 2010), but MLSFH research showed that the effect of testing is more nuanced, with HIV+ showing protective behaviors but HIV– sometimes increasing risky behaviors after learning their status (Delavande and Kohler 2012; Fedor et al. 2015; Thornton 2008). HIV programs sought to increase perceived HIV risk, but our analyses show that many in Malawi overestimate their risk, often concluding that they are positive when...
**Figure 1: HIV prevalence for women aged 35 with different marital histories**


they are not, with positive or negative for implications for HIV prevention (Anglewicz and Kohler 2009; Delavande and Kohler 2015). Little is known about long-term consequences of access to HIV testing and any resulting updates of risk and mortality perceptions, despite being potentially key aspects of surviving the epidemic, and the MLSFH 1998–2013 offers one of the few possibilities to investigate.

**Life-course events:** How life unfolds—by choice or due to unexpected shocks—has major implications for surviving the epidemic (O’Leary and Martins 2000). Figure 1, for example, documents striking differences in HIV prevalence—and thus, the chances for surviving the epidemic—for MLSFH women depending on whether they experienced divorce and/or widowhood (Chae 2012; Kohler et al. 2015b). But the sequence of life-course events matters as well: analyses of MLSFH data showed that early sexual debut, not marrying one’s first sexual partner, and a disrupted marriage increased HIV infection risks for women (Boileau et al. 2009).

**Migration:** Migration deserves special attention as it is both a response to and consequence of the epidemic (Boerma et al. 2002). As elsewhere, MLSFH migrants have significantly higher HIV prevalence than non-migrants. Contrary to the assumption that migration is an independent risk factor for HIV infection, HIV+ MLSFH respondents are more likely to migrate (Anglewicz 2012). And controlling for selection, migration is linked to improved mental—but not physical—health (Anglewicz et al. 2015b). These relations between migration and well-being extend beyond individuals: children of those dying often move to homes of relatives for care (Grant and Yeatman 2012; Hosegood et al. 2007). Rapid urbanization is also related to migration. Malawi is one of the least urbanized countries, but has one of the highest rates of urban population growth (UN Population Division 2015). Through migration and interactions with migrants (e.g., sex or remittances),
urbanization also permeates rural lives and livelihoods. By combining pre- and post- migration data with data on transfers, data that are exceptional in ESA, this paper documents the dual relationship of how migration influenced, and was influenced by, survival and well-being among respondents and their families.

2.2 Beyond individuals

Surviving the Epidemic also depends on:

**Husbands and wives:** Marriage is nearly universal in Malawi, divorce is common, and remarriage is frequent (Anglewicz and Reniers 2014; Reniers 2003). Interactions between husbands and wives are thus among the most important behaviors for surviving the epidemic. Marriage is perceived as a risk for HIV infection, especially for women (Smith and Watkins 2005), and suspicion that one’s spouse was unfaithful is correlated with spouse HIV status (Anglewicz and Kohler 2009). Recent spouse-level MLSFH analysis has proven insightful: Malawians are not passive with respect to these risks through their spouses, and marriage and spouse-level measures (such as spouse’s HIV status, matrilocal or patrilocal residence, spousal communication) are significantly associated with outcomes like divorce and condom use within marriage (Anglewicz and Clark 2013; Anglewicz and Reniers 2014; Reniers 2008). ART, however, may have profoundly changed these husband-wives interactions, with implications for post-ART marriage dynamics (Sully et al. 2015). Due to its dyadic nature including husbands and wives, and the retention of all ever-interviewed respondents in subsequent waves, the MLSFH provides a rare opportunity to study surviving the epidemic as a function of husband-wives interactions during the epidemic up to 20 years earlier.

**Family structures:** Orphanhood affects child and youth outcomes, with considerable controversy in the literature about the magnitudes (Beegle et al. 2010; Chae 2013b; Evans and Miguel 2007; Kidman and Anglewicz 2014). Family structures more generally matter: mortality and morbidity of family members affect the survivors’ well-being (Floyd et al. 2008; Hosegood et al. 2004), and the age- and gender-composition of children can shape access to resources and transfer networks that help buffer shocks during the epidemic (Kohler et al. 2012; Myroniuk et al. 2013). Providing measures of family and household structures from 2004 onward, with more basic information back to 1998, the MLSFH is exceptional in relating survival and well-being of MLSFH respondents to prior family structures.

**Networks and communication:** Social networks are fundamental to individuals’ ability to cope with crises (Ben-Porath 1980; Christakis and Fowler 2009; Unger and Powell 1980). surviving the epidemic has been no exception: MLSFH Ethnographic Journals (Section 3) show that since at least 1999 Malawians made use of their social networks to interpret the epidemic (Watkins 2004; Watkins and Swidler 2009). Networks also provided access to resources to buffer shocks (Kohler and Hammel 2001; Kohler et al. 2012; Myroniuk et al. 2013), and they provided information that facilitated behavioral change, the adoption of innovations such as HIV testing and ART,
Figure 2: Total savings (USD) in the general population, 2006–2010 by distance to ART in the MLSFH; ART is available 2008–

Notes: After ART is available, respondents near ART clinics have higher savings, along with changes in survival expectations, productivity, child human capital investments (Baranov et al. forthcoming; Baranov and Kohler 2014).

and adaptation to new social and epidemic realities (Kohler 2000; Valente 2005). MLSFH research has made critical contributions to this literature based on data on conversational and religious networks, family networks, and networks of potential sources of help in times of crises (Adams and Trinitapoli 2009; Behrman et al. 2002; Godlonton and Thornton 2012, 2013; Helleringer and Kohler 2005; Kohler et al. 2001, 2007, 2015a, 2012; Myroniuk et al. 2013; Trinitapoli and Regnerus 2006; Trinitapoli and Weinreb 2012). While the network literature is rapidly expanding (Christakis and Fowler 2009), rarely does data provide the opportunities offered by the MLSFH: linking extensive information on conversational, family and resource-transfer networks collected during 1998–2010 to survival and well-being up to 2013 (Figure 4). A priori, we expected to find that social networks played multiple roles for surviving the epidemic. Access to information is one and access to resources is another. But network impacts are not always positive: while networks provide transfers that alleviate effects of shocks, they also come with obligations that may negatively affect well-being (Myroniuk and Anglewicz forthcoming; Stroud and Anglewicz 2015). The structure of networks is likely to matter as well: sparse networks facilitated diffusion of information, while dense networks were more likely to provide resources (Granovetter 1973; Kohler et al. 2001).

2.3 Policy responses and health innovations

The MLSFH allows us to document the consequences of a marked discontinuity in policy responses to the epidemic: the expansion of ART, reaching the MLSFH study areas in 2008. ART was embraced by the Government of Malawi, in part due to generous external funding, and the scale-up of ART had a major effect on reducing morbidity and mortality (Figure 3) (Bor et al. 2013; Floyd et al. 2012; Jahn et al. 2008; Payne and Kohler 2015). Recent analyses of geocoded MLSFH data have shown that not only HIV+ benefited from the availability of ART: the widespread ART
roll-out had profound influences also on the HIV– population by reducing perceived mortality risks and uncertainty. As a consequence of changed perceptions, ART seems to have affected important life-cycle behaviors in the general population (savings [Figure 2], investments in children, sexual behaviors), improving mental health, and increasing agricultural productivity (Baranov et al. forthcoming; Baranov and Kohler 2014). If these differences persist, existing studies substantially underestimate the ART benefits by focusing primarily on relatively short-run effects for HIV+ individuals and their families and thus omitting consequential spill-over effects (Beard et al. 2009; Bor et al. 2012; Levinsohn et al. 2011; Lucas and Wilson 2013; Resch et al. 2011; Thirumurthy et al. 2012a, 2008).

3 Data and Context

Malawi provides an opportune environment for research on surviving the epidemic. HIV/AIDS is widespread (Malawi DHS 2011; UNAIDS 2012), including in the MLSFH (Figure 4). The MLSFH cohort was selected in 1998 (with additions in 2004 and 2008) to represent the rural population. Respondents in the most recent waves were primarily middle-aged or older (Figure 4). The cohort is rural, thus representing the contexts where the majority of Malawians (85%) live in conditions similar to those prevailing in other rural SSA LICS: poor health conditions, over-burdened health facilities, and frequently unmet nutritional needs. The MLSFH cohort predominantly engages in home production of crops complemented by small-scale market activities. Malawi life expectancy at birth was 51 for men and 55 for women in 2010, and healthy life expectancy was 7–8 years less (Salomon et al. 2012). Mortality levels among MLSFH respondents, including its recent reversal, corresponds to that of the overall population (Chin 2011; Doctor 2004; Gerland et al. 2007;
Table 1: First available MLSFH Round for MLSFH participants in 2010 (MLSFH 6) and 2012 (MLSFH 7, mature adults aged 45+ only)

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td>Females (%)</td>
<td>Males (%)</td>
</tr>
<tr>
<td>1998</td>
<td>39.79%</td>
<td>35.81%</td>
</tr>
<tr>
<td>2001</td>
<td>9.13%</td>
<td>7.10%</td>
</tr>
<tr>
<td>2004</td>
<td>11.82%</td>
<td>23.53%</td>
</tr>
<tr>
<td>2006</td>
<td>9.18%</td>
<td>11.45%</td>
</tr>
<tr>
<td>2008</td>
<td>20.41%</td>
<td>13.55%</td>
</tr>
<tr>
<td>2010</td>
<td>9.67%</td>
<td>8.57%</td>
</tr>
<tr>
<td><strong>N</strong></td>
<td>2,234</td>
<td>1,564</td>
</tr>
</tbody>
</table>

For more than 46% of the 2010 respondents, and for more than 63% of the 2012 respondents, initial data are available from either 1998 or 2001.

Payne et al. 2013; Payne and Kohler 2015). Despite somewhat lower per capita income, Malawi is similar to other SSA LICs in terms of indicators such as life expectancy, infant mortality, child malnutrition, access to clean water, literacy and schooling (WHO 2013; World Bank 2013).

The MLSFH 1998–2013 is based in three districts (Rumphi in the North, Mchinji in the Center, and Balaka in the South) and is described in a MLSFH Cohort Profile (Kohler et al. 2015b; MLSFH 2015).¹

MLSFH sample selection, sample sizes and research foci during 1998–2013 are reported in Figure 4, along with aspects of the data that are most pertinent for the proposed MLSFH research on surviving the epidemic. Table 1 reports the first available MLSFH survey for participants in the 2010 and 2012 MLSFH Rounds, indicating that for 63% of the 2010 MLSFH participants initial MLSFH data are available from 2004 or prior. The same is the case for the 2012 MLSFH mature adults. The addition of the MLSFH parent sample occurred in 2008, and accounting for about 12% of the 2010 and 26% of the 2012 MLSFH respondents. For about 40% of respondents who were interviewed by the MLSFH at least once, four or more rounds of MLSFH data are available, increasing to 57% and 70% for 2010 and 2012 MLSFH participants respectively. More than 40% of 2010 respondents have data from 5+ MLSFH Rounds, and >80% from 3+ rounds (Kohler et al. 2015b).

The Cohort Profile (Kohler et al. 2015b) provides detailed discussion of MLSFH survey methods, survey instruments, and analyses of attrition. The most common reason for non-interview in the early MLSFH sample was migration, and migrant follow-ups in 2007 and 2013 were conducted to retain these respondents. While focus topics evolved over time, the eight rounds of MLSFH data provide prospective longitudinal data on: household structure and family change (household/family rosters, marriage and partnership histories), human capital (health, schooling, nutritional status), social capital (social networks, intrafamilial/intergenerational and community transfers, social participation), sexual behaviors (sexual relations and networks, HIV risk behaviors and prevention), subjective expectations and well-being (SF12 module, subjective well-being and mental health, HIV risk perceptions, mortality and HIV infection risks), household production and consumption (standard of living, household assets and income, expenditures on health and schooling, time use, migration), and mortality and migration of MLSFH participants.

¹Funding included R01 HD/MH041713, R01 HD37276, R01 HD044228, R21 HD050652, R21 HD071471, R01 HD 053781, R21 HD071471 and Penn PSC, PARC and CFAR support.
### Existing MLSFH data pertinent for proposed MLSFH focus on STE 1998–2020

**Common MLSFH data across all waves**
- Health and well-being, social/economic conditions, human capital, assets and income, marital status and spouse linkages, fertility, sexual behaviors, village characteristics

**MLSFH Primary Research Foci**
- **Throughout 1998–2013:**
  - Social and economic conditions and demographic change, human capital, assets and income, mortality of respondents
- **MLSFH 1-3:** Fertility, HIV knowledge and risks, social networks, social capital, religion and congregations, detailed village characteristics from chiefs
- **MLSFH 4-6:** HIV risks, consequences of poor health on individuals and families, subjective expectations, family networks and transfers data, investments in children
- **MLSFH 7-8:** Mental health and well-being, physical health and performance, cognitive functioning, and aging among mature adults (= respondents aged 45+)

### Existing Data: Malawi Longitudinal Study of Families and Health (MLSFH): 1998-2013

<table>
<thead>
<tr>
<th>Year</th>
<th>MLSFH Wave</th>
<th>2006-10</th>
<th>2012-13</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MLSFH 1-3</td>
<td>MLSFH 4-6</td>
<td>MLSFH 7+8</td>
</tr>
<tr>
<td>1998</td>
<td>2,597</td>
<td>25</td>
<td>42</td>
</tr>
<tr>
<td>2001</td>
<td>2,546</td>
<td>28</td>
<td>44</td>
</tr>
<tr>
<td>2004</td>
<td>3,261</td>
<td>22</td>
<td>43</td>
</tr>
<tr>
<td>2006</td>
<td>3,431</td>
<td>24</td>
<td>44</td>
</tr>
<tr>
<td>2008</td>
<td>4,036</td>
<td>27</td>
<td>53</td>
</tr>
<tr>
<td>2010</td>
<td>3,798</td>
<td>28</td>
<td>54</td>
</tr>
<tr>
<td>2012</td>
<td>1,266</td>
<td>50</td>
<td>67</td>
</tr>
<tr>
<td>2013</td>
<td>1,257</td>
<td>51</td>
<td>68</td>
</tr>
</tbody>
</table>

N = completed MLSFH surveys (excluding migrants)

**(2012+13 included mature adults aged 45+ only)**

**Figure 4: Malawi Longitudinal Study of Families and Health (MLSFH): Data and Analyses 1998–2013**

**MLSFH Key Findings:** The MLSFH has been the basis of more than 230 publications and working papers (see Cohort Profile (Kohler et al. 2015b; MLSFH 2015) and Progress Report Publications), including: social interaction, networks and transfers; subjective expectations about HIV infection and related health risks; HIV testing and counseling; sexual behaviors, HIV risks and prevention strategies; health and mortality; migration and health; and effects of expanding ART access.

**MLSFH Study Location and Study Population:** The MLSFH is based in three districts in Malawi: Rumphi in the North, Mchinji in the Center, and Balaka in the South. The MLSFH started in 1998 with a sample of 1,532 ever-married women aged 15–49 and 1,065 of their spouses. Details of the initial sampling procedure are described in the MLSFH Cohort Profile (Kohler et al. 2015b). In 2001, respondents were re-interviewed, along with any new spouses since 1998. In 2004, in addition to re-interviewing the 1998 and 2001 study population and new spouses, the MLSFH added an additional sample of approximately 1,000 adolescents aged 15–24 to compensate for the aging of the initial MLSFH sample and the underrepresentation of unmarried individuals at adolescent and young adult ages. During the 2008 MLSFH round, a sample of parents of the original MLSFH respondents was added to the MLSFH to increase the suitability of the MLSFH for studying intergenerational aspects and the health of older individuals in Malawi. This study population was re-interviewed in 2010. The 2012 and 2013 MLSFH rounds were restricted to mature adults, defined as individuals aged 45 and over.
and family members (verbal autopsies, migrant tracking). The MLSFH data have been geocoded since 2004, and has included probabilistic expectations—i.e., expectations that can be interpreted as probabilities—for HIV and health-related outcomes since 2006. MLSFH data include spouse linkages (updated at each round), parent-children linkages, and longitudinal linkages of children listed on the family/household roster. HIV testing and counseling (HTC) has been done repeatedly since 2004, and anthropometry (height, weight and BMI) was measured in 2008 and 2012.

In addition, MLSFH Ethnographic Journals were written by participant observers during 1999–present. Developed by Watkins et al. to elicit what people say about AIDS in public spaces (Angotti et al. 2014; Ashforth and Watkins 2015; Watkins 2004; Watkins and Swidler 2009, 2011), these journals reveal that Malawians ask each other the same question that we do in this paper: why did some of their relatives and friends survive and do relatively well, and others did not? Their answers, however, are often not captured by either by our surveys or those of others. Our unique record of public conversations alongside the MLSFH provides contexts and insights to our statistical analyses, helps assess data quality, and is important in its own right as ethnographic evidence of the perceptions and behaviors underlying surviving the epidemic.

4 Analyses

A broad range of qualitative and quantitative approaches are being employed to analyze the MLSFH to understand Surviving the Epidemic, continuing the diversity in disciplinary approaches that characterizes the prior MLSFH research. Qualitative and quantitative analyses are closely integrated, with both contributing to substantive interpretations. Some of the analytic approaches focus on important associations, while others use more sophisticated approaches to identify causal pathways and mechanisms conditional on further assumptions.

4.1 Overview of analytic approaches

Outcomes: The key outcomes are (1) survival and (2) individual and family well-being, for which a broad set of indicators is available in the MLSFH 1998–2013 (Figure 4).

Exogenous variation: While most of the MLSFH represents observational longitudinal data, with appropriate analytic frameworks described below, we highlight exogenous variation in key determinants of surviving the epidemic that our analyses are exploiting: (i) knowledge of HIV status, resulting from randomized financial incentives for learning HIV test results implemented in 2004 (Thornton 2008); (ii) randomized incentives, increasing annual household income by up to $\approx15\%$, awarded as a result of a 2006–07 RCT on HIV risk reduction (Kohler and Thornton 2012); (iii) spatial and temporal variation in infant and adult mortality, identifiable from geocoded MLSFH household data (Kohler et al. 2015b); (iv) variation in access to HIV-testing, ART, health clinics, roads, markets, schools and cell-phone networks depending on respondents’ residence; (v) variation in respondent’s social networks over time as a result of migration and mortality of network partners, and gender/age distribution of children and kin; and (vi) temporal and spatial variation in prices and weather.
Study populations: Several MLSFH study populations are available to explore different aspects of the proposed analyses, including: (i) survival and migration among ever-interviewed MLSFH respondents; (ii) well-being among surviving MLSFH respondents and their families; (iii) household interactions and their implications for surviving the epidemic using husband-wife linked MLSFH data; and (iv) analyses of survival, migration and well-being of household/family members using longitudinal MLSFH household/family rosters.

4.2 Specific examples: Analyses of mortality, well-being and STE using the MLSFH

Qualitative analyses of surviving the epidemic: We are analyzing all the MLSFH Ethnographic Journals for conversations relevant to surviving the epidemic. For example, an initial small pilot in 2001 (unpublished) asked respondents whether they knew anyone in the village who was faithful (all knew at least one person) and then why they were faithful. The primary responses were that “he was born that way”, “her parents raised her well” and “he is very religious.” Using Nvivo-coded journals from 1998 through 2013, we are identifying and analyzing conversations about individual behavior, gender, the influence of context (e.g. men giving each other advice that it is better to have a partner from a village than from a town, as the latter are more likely to be infected), the role of money in risky vs safe sexual behavior, and the influence of social networks, such as participants in a conversation giving advice to each other about how to avoid infection. We are also focusing on changes in these discussions over time, between 1998–2013.

Descriptive analyses of surviving the epidemic: Survival and well-being among MLSFH Respondents 1998–2013: Our analyses initially document the mortality and survival of MLSFH respondents during 1998–2013, and provide analyses of the patterns and trajectory of well-being and physical/mental health during this time period. Associations of survival and well-being with the key factors contributing to surviving the epidemic are being documented (Section 2), including (i) individual characteristics, perceptions and life events, (ii) gender, schooling and wealth, (iii) HIV testing and risk perceptions, (iv) life-course events and migration, (v) marriage transitions, family structures and husband-wife relationships.

Survival and mortality: Malawi 1998–2013: More detailed analyses of mortality among MLSFH respondents and their family members begins with thorough data quality evaluations, including age-validations and resolving whether censored cases between waves are deaths or out-migrants. Uncertainty bounds for mortality estimates are created by treating unresolved censored cases using different assumptions. Comparisons of MLSFH mortality with other mortality estimates are conducted (previous comparisons revealed no significant differences in MLSFH mortality levels (Chin 2011; Doctor 2004; Gerland et al. 2007; Payne et al. 2013; Payne and Kohler 2015)). Age validation is conducted using the multiple reports of ages in the MLSFH (at each wave, and from spouse), and age heaping is addressed through parametric hazard models. Mortality risks and life expectancies are estimated, first using classic non-parametric (life table) methods (Preston et al. 2001), and second via hazard models (Elandt-Johnson 1980; Kalbfleisch and Prentice 1980) of the form \( \mu_x(y) = \mu_0(x + y) \exp[\beta_1 X] \), where \( \mu_x(y) \) is the risk of death at age \( x + y \) for those age \( x \) at the...
beginning of each inter-survey period, \( \mu_0(x + y) \) is a suitable baseline hazard allowing for AIDS mortality concentrated at adult ages; \( X \) captures respondent characteristics. Time-varying characteristics and clustering within families is incorporated, and cause-specific estimates (AIDS-related vs non-AIDS-related mortality) is obtained using the MLSFH verbal autopsies.

Most importantly, given the rich longitudinal data that distinguishes the MLSFH from HDSS and other studies of mortality in ESA (Bor et al. 2013; Floyd et al. 2012; Jahn et al. 2008; Larson et al. 2014; Mwagomba et al. 2010; Reniers et al. 2014), our approach allows us to investigate if the factors hypothesized earlier to be associated with surviving the epidemic (Section 2) were indeed predictors of survival: schooling and wealth, life course events and sequencing, HIV testing access and ART, intrahousehold interactions, social networks and kinship availability/structures. We are investigating if these factors differentiated groups in terms of post-ART mortality change.

In contrast to the geographically-restricted HDSS sites, we are able to the MLSFH Migration Follow-ups (Anglewicz et al. 2015a) to examine whether out-migrant health selection is occurring, and how it affects observed mortality levels in the MLSFH study areas. Due to a general lack of out-migration follow-up data, very few studies have been able to directly measure such effects, in ESA or elsewhere (Palloni and Ewbank 2004; Rubalcava et al. 2008; Turra and Elo 2008). To do so, we are constructing a time-varying variable \( Z(y) \) that switches from 0 to 1 at migration. We are then estimating \( \mu_x(y) = \mu_0(x + y) \exp[\beta_1 X + \beta_2 Z(y)] \), where \( \beta_2 \) is the key parameter indicating the impact of out-migration on mortality, after adjusting for \( X \). If positive migrant health selection is occurring, we expect the hazard ratios indicated by \( \beta_2 \) to be significantly below 1.

Well-being and mortality across the life-course: To jointly investigate well-being and survival across the life-course in a dynamic perspective, we are estimating multi-state life tables (MSLT) (Brown et al. 2012; Cai et al. 2010; Schoen 1988; Wolf 1986; Zagheni 2011) that model mortality and transitions between different well-being states (defined by physical health, mental health, labor force participation, marital status, etc). These analyses build on our earlier applications of this method (Kohler et al. 2015c; Payne et al. 2013; Payne 2015). MSLTs are estimated using microsimulation based on the Stochastic Population Analysis for Complex Events (SPACE) software (Cai et al. 2010). In essence, these models project a synthetic cohort population \( P \), disaggregated by age, sex and well-being status, using \( P_t = Q \cdot P_{t-1} \), where \( Q \) is a projection matrix containing all age- and gender-specific well-being transitions rates and mortality rates (Schoen 1988). The key findings of these models related to our theme of surviving the epidemic include age-patterns of mortality by well-being status, age- and gender-specific transition rates between well-being states, estimates of the person-years spent in different well-being states along with estimates of healthy life expectancy as a function of individual characteristics. The rich MLSFH data until 2013 provides a detailed characterization of different dimensions of well-being, thereby moving beyond simple health-based measures, and an exceptionally long time horizon. MSLTs, with their underlying age and state-specific transition probabilities, also enables us to study interactions of well-being and survival in a dynamic perspective (e.g., differences in survival rates by physical or mental health or family structure), including changes in survival and well-being dynamics resulting from the availability of ART or other policy and socioeconomic changes.
Investigate the causal effects of innovations in health on survival and well-being: We are also analyzing the consequences of improved access to ART on survival and well-being in the general population and those HIV+ using geocoded respondent residences, which, combined with geocoded clinic data, allow us to compute distance to nearest ART clinics (and changes therein over time) for each respondent. This accurate measurement overcomes a limitation of related studies based on (perturbed) sampling-area distances (as in DHS) that are subject to considerable measurement error (D’Adda et al. 2009; Friedman 2013; McLaren 2012; Thirumurthy et al. 2012a,b, 2008). Since few MLSFH respondents own motorcycles or bicycles, distance is a good proxy for access to ART (and costs of access). The effects of ART access on well-being $y$ in both HIV+ and HIV− individuals are based on a difference-in-difference identification strategy $y_{ijt} = \alpha_{ij} + \delta_1 POST_t \times PROX_{ij} + \delta_2 POST_t + \delta_3 X_{ijt} + \mu_i + \epsilon_{ijt}$, where $i$ indexes respondents, $j$ indexes villages, $t$ indexes time, and $\mu_i$ are individual fixed effects. POST is an indicator for periods after ART arrives and PROX is the respondent’s proximity (inverse distance) to ART. There is evidence that the Government did not target ART in rural areas according to HIV prevalence. The identifying assumption then is that individuals near and far from ART are subject to similar unobservable trends, an assumption that we have evaluated using pre-ART levels and trends in well-being, physical/mental health, etc (Baranov et al. forthcoming).

5 Conclusions

Across Eastern and Southern Africa (ESA), a remarkable cohort is reaching middle and older ages: those who have survived the AIDS epidemic. Nobody could escape an epidemic that was devastating for both its health and social implications. Were the survivors of this cohort just lucky? Or did they systematically differ in critical characteristics? What promoted survival and resilience in such a terrible context, and what influenced well-being among the survivors and their families? How did the children of survivors fare, and how did orphans? And for all of these questions, did the epidemic cause persistent divergences in families’ well-being because misery reinforced itself? These and related questions about “Surviving the Epidemic” (STE) are being studied by exploiting an unusually rich data source: the Malawi Longitudinal Study of Families and Health (MLSFH) cohort, 1998–2013.

While there has been extensive research on determinants and consequences of HIV, determinants of ART uptake, and individual-level benefits of ART, there has been no integration of these topics into an over-arching framework of resilience (Walsh 1996) that would provide understanding of why some survived and others did not, and why some individuals and families fare much better near the end of the epidemic than others. Outside the MLSFH, few other datasets would permit pursuing this paramount question. It requires longitudinal data covering the epidemic from its rise to the current decline, and detailed data on life-course transitions, family contexts, social networks and social/institutional environments throughout this period. By combining these ingredients, the MLSFH (Figure 4) provide an exceptional opportunity for studying surviving the epidemic, one that is not available from Health and Demographic Surveillance Sites (HDSS) (INDEPTH Network 2015), DHS (Measure DHS 2015) or other ESA data.

Our analyses are focusing on well-being, mortality & morbidity during 1998–2013, and relate
these outcomes to key social, demographic and economic contexts that MLSFH respondents have experienced during the rise, peak and recent decline of the AIDS epidemic: family & household dynamics, social capital & networks, household production & consumption, and intergenerational relations. Using the MLSFH 1998–2013 and diverse methodological approaches for longitudinal data—ranging from ethnographic journals to survival models, multi-state life-table models, fixed-effect analyses, and econometric structural equation models—this paper is among the first to identify the factors influencing survival, resilience and well-being among MLSFH respondents, their children, and other family members.

Future global health crises are certain, and better understanding how low-income country citizens cope with such crises, and how policies and programs can enhance these strategies is essential. This paper makes an important contribution to this issue by documenting, based on the MLSFH, from 1998–2013: what predicted survival, and factors influencing resilience and well-being among the cohort of individuals (and their families) who survived the AIDS epidemic and are now reaching middle to old age in Eastern and Southern Africa.

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